

My personal information

This resource explains your rights to see and have copies of your personal information, and how to complain if access to your records is refused or if what is written about you is wrong.

Please note:

- This guide only covers accessing personal information from the point of view of a person with a mental health problem.
- This guide applies to England and Wales.
- This guide contains general legal information, not legal advice. We recommend
 you get advice from a specialist legal adviser or solicitor who will help you with
 your individual situation and needs. See Useful contacts for more information.
- The legal information in this guide does not apply to children unless specifically stated.

If you require this information in Word document format for compatibility with screen readers, please email: publications@mind.org.uk

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Quick facts

- If you have a mental health problem you may want to see what information an
 organisation keeps on file about you (including employers, doctors, hospitals,
 social services and the police).
- You usually have a legal right to access <u>personal information</u> (sometimes called personal data) held about you by an organisation. This right is protected by the <u>Data Protection Act 1998</u> and <u>General Data Protection Regulation (GDPR)</u>
- There are some <u>situations where an organisation is allowed to withhold your personal information</u> from you (not share it).
- To <u>access your personal information</u> you need to make a request in writing, called a <u>subject access request</u>.
- As of 25th May 2018 organisations have one calendar month to respond to your subject access request, and they are not usually allowed to charge you a fee for supplying your data. (Before this date the time limit was 40 days, and they could charge you up to £50.)
- If your request is refused or ignored, you should <u>write to the organisation</u> to remind them of their obligations. If they still don't give you what you've asked for, you should <u>complain to the organisation</u>.
- If you don't receive a satisfactory response to your complaint, you can <u>complain to</u> <u>the Information Commissioner's Office (ICO)</u>.

Terms you need to know

Term	Meaning				
Advocate	An advocate is a person who can both listen to you and speak for you in times of need. Having an advocate can be helpful in situations where you are finding it difficult to make your views known, or to make people listen to them and take them into account.				
Attorney	Find out more on our <u>advocacy information page</u> . An attorney is a person over the age of 18 whom you have				
Allorneg	appointed to make decisions on your behalf about your welfare and/or your property and financial affairs. You need an attorney if you are unable to make such decisions yourself. If you do not have the <u>capacity</u> to appoint an attorney, the <u>Court of Protection</u> will appoint a deputy to perform this role.				
	 A health and welfare attorney makes decisions about things like your daily routine, your medical care, where you live and, if you specially request this, whether you should have life-sustaining treatment. A property and financial affairs attorney makes decisions about things like paying bills, collecting benefits and selling your home. 				
Capacity	'Capacity' means the ability to understand information and make decisions about your life. Sometimes it can also mean the ability to communicate decisions about your life.				
	If you do not understand the information and are unable to make a decision about your care, for example, you are said to lack capacity.				
	See our legal pages on the Mental Capacity Act 2005 for more information.				
Court of Protection	The Court of Protection makes decisions and appoints deputies to act on your behalf if you are unable to make decisions about your personal health, finance or welfare.				
Data Protection Act 1998	The Data Protection Act 1998 is the law that gives you rights to look at and have copies of information held about you by various organisations and agencies.				
Data subject	This is the person to whom the information relates. If you want to access information held about you, then you are the data subject.				
Enforcement notice	A document sent to an organisation by the <u>Information</u> <u>Commissioner's Office</u> setting out the action it needs to take to comply with its obligations under the <u>Data Protection Act 1998</u> . Failure to comply with an enforcement notice is a criminal offence which can result in a fine.				

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General Data Protection Regulation (GDPR)	Regulations in force from 25th May 2018 which tell organisations how they can use your personal information. Also gives you rights to access, correct and erase personal information held about you.
Health record	Any record of information relating to your physical or mental health that has been made by or on behalf of a health professional.
Inaccurate data	Information that is incorrect or misleading as to any matter of fact.
Information Commissioner's Office (ICO)	The independent body responsible for making sure that organisations comply with their obligations under the Data Protection Act 1998 .
Manifestly unfounded or excessive	If you make a <u>subject access request</u> that is 'manifestly unfounded or excessive' the organisation can refuse or ask you to pay a fee. This could include where your request is for an unnecessarily large amount of information or is the same as a recent request you made.
Personal information (or personal data)	Information which relates to you in such a way that you can be identified from the information. It might be held on computers, in emails, be printed, in handwritten documents, in photographic images, videos or audio recordings.
Redact	This means removing the relevant information. It can be done by crossing through the relevant information with a black marker pen and then photocopying the document or by using a computerised programme specially designed for this purpose.
Subject access request (SAR)	A written request to an organisation asking for details of the personal information they hold about you.

What are my data rights?

Do I have a right to access my personal information?

Yes, you have a legal right to access <u>personal information</u> held about you by an organisation.

This right is protected by the <u>Data Protection Act 1998</u> and <u>General Data Protection</u>

<u>Regulation (GDPR)</u>. These deal with your rights regarding information held about you by various organisations and agencies, including:

- GPs
- hospitals
- social services
- the police
- your employer
- the Department for Work and Pensions.

However, there are some <u>situations where an organisation is allowed to withhold</u> <u>personal information from you</u> (not share it).

What records do I have a right to see?

You have the right to ask an organisation:

- what, if any, personal information it holds about you
- why it holds that information
- who it may be sharing your information with
- where the information came from
- for an explanation of any technical or complicated terms relating to the information.

You also have the right to see the information held about you and/or to be given copies of it. This includes both computerised and paper records.

What format should the records be in?

The organisation must provide copies of your records in a permanent form (for example photocopies, or digital copies on a USB memory stick or on a disk) – unless you have agreed to the information being provided in some other way (for example, viewing it at the organisation's offices).

If you want the information in a particular format (such as on an encrypted USB memory stick), it's worth saying so when first making your request.

When is an organisation allowed to withhold information from me?

There are some specific situations where organisation is allowed to withhold personal information from you (not share it). These include:

- if your request is 'manifestly unfounded or excessive'
- if it includes personal information about someone else (third party information)
- if sharing it would be likely to cause serious harm to you or another person
- if sharing it would make it harder for the police to <u>prevent crime or prosecute</u> criminals.

If an organisation is refusing to share information with you for one of these reasons, they should write to you and explain why.

Manifestly unfounded or excessive requests

Organisations must usually make proper efforts to find all the information you have requested. They can't refuse your request purely because it will be inconvenient for them or require some work.

However, they don't have to comply with any requests that are 'manifestly unfounded or excessive'. This could apply if:

- you request more information than you actually need
- you make repeated requests for the same information.

If an organisation thinks your request is excessive it should ask you to be more specific rather than refuse you outright.

Example

Keeva is unhappy about a visit from her social worker two months ago and is thinking about making a complaint. She has requested a copy of her social services file, which goes back over twenty years. If Keeva only needs the information for the complaint the local authority might say that her request is excessive. If Keeva needs all of her records she should explain why in a letter.

Third party information

If the records you have requested about yourself also include personal information about someone else (a third party), the organisation doesn't have to share it unless:

- the other person mentioned has agreed for the information to be shared, or
- it's reasonable for the organisation to share the information anyway without the other person's agreement. To make this decision the organisation has to weigh up your right to see your information against the other person's right for information about them to be kept confidential.

One way around this problem may be for the organisation to <u>redact</u> information that would identify the third party (so you couldn't see those bits, but could still see everything else).

But information that identifies a health or social care professional should not usually be redacted (for example, the names of doctors who conducted an assessment under the Mental Health Act).

Serious harm to you or another person

You usually have the right to see your <u>health records</u> (sometimes called medical records) and any information held about you by social services.

The exception to this is if sharing that information with you would be likely to cause serious harm to your mental or physical health, or that of another person.

An organisation can only use this as a reason for not sharing your information after assessing how likely it would be to cause you or another person serious harm. This would usually involve consulting with the health professional responsible for your care (or the care of the person they're concerned about).

You can find information on how to access medical records on the NHS Choices website.

Example			

Amir is 16 years old. He is looked after by social services under a Care Order. Amir has a history of self-harming following contact visits with his birth family. He's not seen his birth family for 6 months and has not self-harmed during this time.

Amir asks to read his social services records. But his social worker is concerned that there's information in these records about Amir's birth family which may distress him and lead to him self-harming again.

In this situation, social services may choose not to share some of Amir's social services records with him as it may cause serious harm to his mental or physical health. Alternatively they could invite Amir to look at his records at the social services offices, with the support of his social worker.

Preventing crime or prosecuting criminals

You usually have the right to find out what personal information is held about you by the police.

However, the police don't have to share your information with you if doing so would be likely to make it harder for them to:

- prevent or detect crime for example, where the information is relevant to an ongoing police investigation
- capture or prosecute offenders.

Can I access personal information about someone else on their behalf?

You usually don't have the right to access personal information about other people.

The exceptions are:

- If you manage the affairs of a person who lacks <u>capacity</u>, (as an attorney or someone appointed by the <u>Court of Protection</u>). In this case you should be able to access that person's information on their behalf. You will need to provide the organisation with copies of appropriate paperwork to show that you have this authority.
- If you are a parent with parental responsibility. In this case you can access personal information on behalf of your children, but the subject access rights are the child's. If the child understands what it means to make a <u>subject access</u> request and how to interpret the information they receive as a result, the organisation would expect the subject access request to be made by the child.

How do I access my records?

How do I get copies of my records?

You almost always need to make a request to see your records in writing. This is called a subject access request (SAR).

A subject access request can be:

• an email or a letter requesting copies of your records

Sample subject access request letter

Download a sample subject access request letter (Word doc or PDF).

- a standard form an organisation may have to request access to records
- a non-standard form, such as through an organisation's website or social media
 account for example Facebook or Twitter. However, this may lead to a delay in
 your request being dealt with, as it's unlikely that the team responsible for social
 media will be the same team responsible for dealing with subject access requests.
 This means they may not recognise your request as a subject access request.
 There may also be practical difficulties in relation to you being able to prove your
 identity if you make your request in this way.

Under <u>equality law</u> organisations have a legal duty to make their services accessible. If your mental health problem makes it impossible (or unreasonably difficult) for you to make a request in writing, an organisation may have to make a <u>reasonable adjustment</u> to its normal data protection policy. This could mean that it treats a verbal request as a valid subject access request.

When preparing your subject access request:

- Provide enough detail about the records you wish to see. If your request is too
 vague, the organisation might ask you to be more specific. This could cause a
 delay in getting the information you want.
- Think about exactly what you want to see for example your social services records for a particular period of time or medical records held by a particular doctor.
- Avoid asking for information that is too general for example "all information that
 the Council holds about me". Although you can ask for this, you may end up with
 information that is not relevant. It might be better to ask for all of the records held
 by a particular service or department for example "all of my social services
 records" or "a copy of my personnel file". It's a good idea to mention that you're
 making a <u>subject access request</u> under the Data Protection Act 1998.
- Send your request by recorded delivery or by email. This will mean that you have
 proof of the date your request was sent. You should also keep a copy of your
 letter or subject access request form, and any other relevant correspondence.
 This will be important evidence if you need to make a complaint.
- **Provide proof of identity**. The organisation needs to make sure that you are who you say you are. You might be asked for a photocopy of your passport, driving license or a utility bill. However, if the person you make the request to knows you well, you shouldn't need to provide detailed proof of your identity.

How long will it take to get a response?

As of 25th May 2018, organisations have **one calendar month** to respond to your <u>subject access request</u> starting from the day they receive your request (before this date the time limit was 40 days).

If the organisation thinks that your request is very complicated then it can extend this to three months, but they must write to you to explain why the extension is necessary.

Will I have to pay?

As of 25th May 2018, organisations are **not allowed to charge a fee** for supplying your data unless your request is <u>manifestly unfounded or excessive</u> (before this date organisations could charge up to £50.00).

If an organisation decides it is appropriate to charge you for an excessive request, the amount must be based on how much it will actually cost them to fulfil your request.

Subject Access Requests: Quick Checklist

- 1. Think about the personal information you wish to see.
- 2. Identify which organisation holds this.
- 3. Check their website or call them to find out:
 - who to send the subject access request to
 - whether the organisation has a standard subject access request form
 - what form of proof of identification the organisation needs.
- 4. Draft your subject access request letter or complete the form (if the organisation has one).
- 5. Send to the relevant contact at the organisation with proof of identification. Ideally, send the request by recorded delivery so that you can track the request.
- 6. Keep a copy of the letter or subject access request form you have sent.
- 7. Put the deadline for them to get back to you in your diary **one calendar month after** receipt by the organisation.

Tip: If you can send appropriate proof of identity at the same time as making your subject access request, it should make the process quicker.

Example

Audrey experiences severe anxiety and depression. She also has a diagnosis of rheumatoid arthritis.

For some years now, Audrey has received support from social services with daily living tasks, including bathing, managing her money and getting out and about in the community.

Her package of care has recently been cut by social services. Audrey has an <u>advocate</u> who is going to assist her with making a complaint about this.

The advocate has suggested that it would be a good idea for Audrey to get copies of her social services records. Audrey has received support from social services for the past 15 years, so her records are likely to be extensive.

The decision was made 6 weeks ago. Audrey will need to see the records that relate to this decision and there will probably be records from before the date of the decision which are relevant. However, she is unlikely to need copies of her social services records in their entirety.

Audrey could make a request for copies of her records from the past 6 months. She may not need to provide proof of identity if she makes the request to her social worker as her social worker knows her well.

What if I don't get what I asked for?

What can I do if my request is refused or ignored?

You should always receive a response of some kind to a <u>subject access request</u>. Even if the organisation holds no information about you, or it has a <u>reason to withhold your information</u> from you (not share it), it must still write to you and explain that this is the case.

If more than one month has passed since you made your subject access request and you've not heard anything back, you should follow these steps:

- Step 1: Write to the organisation reminding them of your request, and of their obligations under <u>General Data Protection Regulation (GDPR)</u>. The <u>Information Commissioner's Office</u> (ICO) have a standard template letter for this <u>here on their website</u> (scroll down to 'What can I do if the organisation does not respond?'). It's a good idea to set the organisation a further reasonable deadline for responding to your request for example 7 or 14 days.
- Step 2: Make a complaint to the organisation. If you still don't hear back from them after writing to them to remind them of their obligation, you should complain directly to them using their complaints process.
- Step 3: Complain to the Information Commissioner's Office (ICO). If you aren't happy with their response to your complaint, and you still believe that they should share the information you've asked for, you can complain to the ICO.

What can I do if an organisation doesn't send me everything I asked for?

You should write back to the organisation explaining what information you think is missing. You should be as specific as possible.

Template letter

The ICO website has a template letter you can use (scroll down to 'What can I do if I believe the organisation has not sent me all the information I am entitled to?').

If you aren't happy with the organisation's response, and you still believe that it has failed to share all of the information you asked for, you can complain to the ICO.

What can I do if an organisation takes too long to provide my information?

There is a <u>one month time limit</u> to provide the information you ask for. If an organisation takes any longer than this, you can report it to the <u>ICO</u> using <u>this form on its website</u>.

If the ICO receives many reports from different individuals about a particular organisation's failure to meet the one month time limit, they may take action against the organisation for failing to meet its obligations under <u>GDPR</u>. Find out more about <u>how the ICO ensures organisations meet their information rights obligations</u>.

What if the information in my records is wrong?

Under <u>GDPR</u> you have a right to 'rectification' of your records. This means that if something in your records is wrong, you can ask to have it corrected. Your request doesn't need to be in writing but it may be helpful if it is.

The organisation has one month to respond to your request. If they think your request is manifestly unfounded or excessive they may charge you a fee or refuse your request.

However, there's a difference between information that is wrong and information that you disagree with.

If you disagree with a medical opinion in your health records:

- You cannot force the organisation to change or remove the record. This is because
 it's a record of an opinion expressed by a medical professional at a particular point
 in time. Even if their opinion is proved wrong at a later date (for example, if your
 diagnosis is revised), the old record won't necessarily be removed.
- You can ask for a note to be added to your record. You can write to the organisation that holds your health records and ask that a note is added, stating that you disagree with the views expressed. If the organisation refuses to record your objections, you can make a complaint to the ICO.

If you're not happy with their response, you can make a complaint to the ICO.

Making a complaint to the Information Commissioner's Office (ICO)

How do I make a complaint to the ICO?

The <u>Information Commissioner's Office</u> (ICO) is an independent body responsible for making sure that organisations comply with the <u>Data Protection Act</u> and <u>General Data Protection Regulation (GDPR)</u>. The ICO also deals with concerns raised by members of the public about the way in which organisations look after personal information and deal with subject access requests.

You can complain to the ICO if an organisation:

- fails to respond to your request for disclosure
- refuses your request
- fails to send you all of the information you asked for
- fails to comply with the one month time limit for disclosure.

The ICO will always expect you to have <u>raised your concerns with the organisation</u> before submitting a complaint.

The ICO has a <u>form on its website</u> which you can use to make your complaint. When you send the form to the ICO, include all the communications you've had with the organisation about your request for disclosure, including copies of the documents raising your concerns.

- If you have this saved electronically, you can submit the form and the correspondence by email to casework@ico.org.uk
- If you only have paper copies of the correspondence, you will need to send it along with the form to Customer Contact, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.
- You can call the ICO helpline on 0303 123 1113 (local rate).

You should make a complaint to the ICO within three months of your last proper contact with the organisation concerned.

What powers does the ICO have?

If the <u>ICO</u> thinks that an organisation has failed to comply with its obligations under the <u>Data Protection Act</u> or <u>GDPR</u>, it can:

- Write to the organisation and ask it to sort out the problem.
- Take action against the organisation concerned. The ICO may do this in extreme situations where there has been a serious breach. This may include sending the organisation an <u>enforcement notice</u> and imposing a financial penalty.

However, the ICO cannot award you compensation. You can only claim compensation by taking an organisation to court.

Can I take an organisation to court?

You do have the right to take an organisation to court for failing to respond appropriately to a <u>subject access request</u>, but you need to be able to show the court that you tried to sort things out directly with the organisation first.

It's rare for things to get to this stage, as you should be able to sort the problem out by complaining to the ICO.

What can I ask the court for?

You can ask the court to order the organisation to put things right – for example to:

- disclose the information that you have requested
- pay you compensation for harm and distress caused to you as a result of the organisation's actions.

Legal aid

There's no legal aid available for this kind of court application so you would have to fund the case yourself, which could be costly. That's why you should always get specialist legal advice from a solicitor before making an application to court.

More information

- See Useful contacts for more information on finding a solicitor.
- The ICO website has further information which you may also find useful.

Useful contacts

Mind's services

- Helplines all our helplines provide information and support by phone and email.
 Our Blue Light Infoline is just for emergency service staff, volunteers and their families.
 - o Mind's Infoline 0300 123 3393, info@mind
 - o Mind's Legal Line 0300 466 6463, legal@mind
 - o Blue Light Infoline 0300 303 5999, bluelightinfo@mind
- Local Minds there are over 140 local Minds across England and Wales which provide services such as <u>talking treatments</u>, <u>peer support</u>, and <u>advocacy</u>. <u>Find your local Mind here</u>, and contact them directly to see how they can help.
- **Elefriends** is a supportive online community for anyone experiencing a mental health problem. See our <u>Elefriends page</u> for details.

Information Commissioner's Office

Helpline: 0303 123 1113

ico.org.uk

The ICO website contains general useful information about accessing your personal information. You should contact the ICO if you want to make a complaint about an organisation not meeting its obligations under the <u>Data Protection Act</u> or General Data Protection Regulation (GDPR).

The Law Society

020 7242 1222 (England) 029 2064 5254 (Wales) lawsociety.org.uk

The Law Society provides details of solicitors you can get in touch with for specialist legal advice.

Find an advocate

An advocate is a person who can both listen to you and speak for you in times of need. Having an advocate can be helpful in situations where you are finding it difficult to make your views known, or to make people listen to them and take them into account.

For information on advocacy services and groups in your area, you could start by contacting the Mind Legal Line and your local Mind.

Read more about how advocacy might help you.

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