healthwatch

Obtaining consent

September 2020

Introduction

Local Healthwatch speak to many people in a variety of settings and situations. This could be through everyday tasks and conversations or via targeted research and engagement.

Whenever we ask people about their experiences of health and care services or otherwise gather information about people, we must consider:

- Do we need to collect and record personal data?
- Do we need consent?
- How will we obtain, record and store a record of that consent?

This guidance will help you to understand and answer these questions.

What do we mean by 'consent'?

Consent is the agreement to the processing, obtaining, recording, holding, accessing/reviewing, altering, using, sharing, or disclosing of personal data relating to the individual.

To have given consent the person must have been made aware of what their data will be used for and how long it is stored and agreed to do it.

Consent must be 'informed'. This means that it must be reasonable to believe that the person understands what they are being asked to consent to and understand the likely implications of giving or withholding their consent.

Consent must be given freely, not under duress or threat.

As a general principle, we will want to process personal data in ways people are aware of, happy with, and agree to.

Types of consent

There are two types of consent:

- Explicit – for example signing a consent form, saying yes or nodding.
- Implied – for example the person knows what you will do with the information and goes on to disclose that information anyway.

Failure to act **cannot** be taken as consent. We advise that you use a consent form to clarify the action.

When are you able to breach confidentiality?

A duty of confidentiality arises where one person receives information about another and the information is either not public knowledge or property, disclosing the information carries a risk of harm or was disclosed in circumstances requiring confidentiality.

You can breach confidentiality in the following circumstances:

- If you have contacted the participant since the original consent was signed to gain permission from them to use their information for an additional purpose (that was not indicated at first).
- To protect someone from serious harm
- If there is an over-riding public interest or need. For example, if details of abuse were disclosed by the participant during a Healthwatch Enter and View

- For the prevention or investigation of a serious crime

In such circumstances, you must also ensure that there is a lawful basis for your action under Article 6 of GDPR (and Article 9 for special categories of personal data).

In other circumstances, you should give careful consideration, refer to guidance, seek legal advice if needed, and keep a record of your decision to disclose.

General Data Protection Regulation (GDPR)

The GDPR requires that personal data shall be processed lawfully, collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes.

An additional lawful basis under Article 9 must also be met for the processing of 'special categories' of personal data – which includes a person's health information (which also includes information about ethnicity, religion and sexuality).

If you are relying on consent for GDPR compliance purposes, it is your responsibility to be able to demonstrate that this consent has been obtained. This consent must be:

- Given freely
- Informed
- An unambiguous indication of the data subject's wishes
- Given using a statement or affirmative action in agreement of processing their data

Consent, under GDPR, can be withdrawn at any time. It is therefore important to consider whether other lawful reasons for processing the data apply and can be relied upon for GDPR compliance.

For more information on the GDPR refer to the Healthwatch England Data Protection Guidance.

What counts as personal data?

'Personal data' is information which relates to a living person and from which that living person can be identified. Information relating to a deceased person does not constitute personal data and therefore is not subject to the GDPR. Names, email addresses, NHS numbers or other unique identifiers, communications from or about a person, records of a telephone conversation are all personal data.

For example:

If Mrs Patel tells you about her own experiences, and those of her husband, with their GP (Dr Smith) your record of the conversation will contain the personal data of Mrs Patel, Mr Patel and Dr Smith.

For more information on personal data and data protection compliance please refer to the Healthwatch England Data Protection Guidance.

What to include when you're asking for consent

You must inform people about how and why you are processing their personal data. To do this you can:

- Be clear and concise, using plain language that is easy to understand

- We must explain who we are. If Healthwatch is not the 'controller' responsible for the personal data (i.e. if you are collecting data on behalf of another organisation) they must be identified too
- We must give them our contact details and tell them who our Data Protection Officer is.
- We must specify the reason why we want to use a person's data and for what purpose(s), including telling them about anyone we are likely to share their data with
- We must tell them how long we will keep their personal data
- We must tell them if their data will be processed outside of the European Economic Area.
- We must tell them about their rights such as:

    a. Their right to access their personal data
    b. Their right to have inaccurate data corrected
    c. Their right to have their personal data deleted or place restrictions on its use
    d. Their right to complain, including their right to refer their complaint to the Information Commissioner's Office

Depending upon the circumstances, you may be required to provide additional information specified under GDPR Article 13 and Article 14.

Where you receive personal data via a third party (e.g. if someone tells you about a relative's care and you are making a record of this) you must notify the 'data subject' within a reasonable period, unless it is impossible or would require a disproportionate effort to do so.

For more information on data protection compliance please refer to the Healthwatch England Data Protection Guidance

When do we *not* need consent?

It is important to consider whether the need is proportionate or appropriate to avoid unnecessary data collection and management. Storing personal data can bring a degree of risk, and if a project can be conducted as effectively without gathering personal details then you must avoid doing so.

Where we decide that we do need to collect personal data, we should seek consent and process the data in accordance with people's wishes - other than in exceptional circumstances where this is not possible or appropriate.

Such circumstances where we may decide *not to* seek consent include:

- Where that person's information is part of someone else's experiences of care. For example, information about the actions of identifiable health professionals shared with us as part of a patient's experiences of receiving care. Consider whether it is necessary to record this information.
- Where a relative, carer or friend tells us about another person's care on their behalf. Before recording that other person's personal data, ask whether they know and are happy for us to do so.
- Where a person is happy to speak to us but may themselves lack capacity to consent under law. For example, when undertaking research with a person with a significant learning disability or living with dementia. It is very important to understand and act upon these people's experiences of care, but careful consideration should be given to ensure that the individual is properly protected and that we're acting in their best interest.

When do we need consent?

Reusing personal data

If you decide that you wish to use someone's personal data for a reason that they were not informed of and did not consent to at the start, then you will need to contact them to get consent.

For example:

David shares his experiences of using a rehabilitation service with you so that you can use this for Healthwatch's core functions. A few months later you decide that your Healthwatch service would like to support a research project looking at the impact of funding decisions on this type of service. You may share anonymised data with the researchers, but you would need to recontact David and seek his explicit consent if you wished to pass his contact details or other personal data on to the researchers.

Audio-visual recordings and photographs

Consent must be obtained when you record/photograph someone and plan to use the images later. If the individual can be clearly recognised, and is intended for use in the public domain, you must:

- Explain the purpose of recording/photographing, and whether images will be shared and reused
- Keep evidence of who, when, what and how consent was obtained
- Inform the participant of how long their image will be used for and what will happen to the images when this period ends (e.g. it will be deleted). It should be clearly communicated that the image may remain in publication for longer than expected, and that it may remain in existing publications even if they withdraw consent

A template information and consent form for photography can be found here.

If people are included in the photograph incidentally, and unlikely to be identified, you don't need to seek consent.

At events where photography and videography are present, make sure you have signs to make people aware.

Mailing lists

Things to consider:

- Someone can be contacted as part of a mailing list only if they have given consent to receive emails from you (e.g. by ticking an opt-in box).
- Automatically pre-ticked boxes do not give valid consent. You must use an affirmative method of getting consent.
- Make sure your list of people who have 'opted out' of the mailing lists are fully up to date.

Observation

Collecting data by observation relies on observing behaviour without the person's knowledge. This should only be done in a location where people would normally expect to be in public view.

Consideration should be given as to whether it is appropriate or necessary to obtain consent after the study has taken place.

Ways to obtain consent

How we go about obtaining consent will depend upon the circumstances.

Information sheet

To obtain, record and manage consent, Healthwatch should provide people with an information sheet and consent form written in plain English that is easy to understand. The information sheet must provide enough and appropriate information on which the participant can base an informed decision as outlined above.

The information sheet should include:

- Who is conducting the research/information gathering exercise? This should also include details of the Data Controller (an organisation that makes decisions about the purpose(s) for which, and the way in which the data is processed).
- A clear explanation of the purpose of the research and what the person is required to do.
- A description of how the information will be used during research, distribution, publication, how the data will be stored and how long for.
- A statement that informs the individual that they have the right to withdraw both at the time, and afterward.
- Contact details for if they wish to withdraw from the project or make a complaint.

If you're conducting activity that requires consent online, you can provide this information by linking to your privacy statement. Guidance on how to write a privacy statement and a template can be found here.

Consent form

The consent form is used to record the consent process and a person's agreement to take part in the project.

Statements to include:

- The participant has read and understood information about the project.
- The participant has been given the opportunity to ask questions.
- The participant voluntarily agrees to participate in the project.
- The participant understands that they can withdraw at any time.
- The participant is aware of how the data will be used in publications.
- The participant understands how the data will be kept confidential (e.g. anonymised).
- The participant agrees with archiving and reuse of the data.
- The participant and the researcher provide signatures with date of signage.

The individual should be given a copy of the form and the researcher should retain the signed original. The original consent forms can be digitised and stored securely, permitting the original copies are destroyed securely in accordance to your Healthwatch policy.

For a template information sheet see here.

For a template consent form see here.

Speaking to people on the phone

It is good practice to have a consistent process when talking to people over the phone. When we collect people's information over the phone, we can use a data processing script. This will ensure that we are providing appropriate information in the same way to everyone we talk to.

For example scripts that you can use, see here.

Obtaining consent from different people

Adults who may not be able to make decisions themselves

It is important to keep in mind that some people may not be able to make decisions themselves and so lack the capacity to consent.

If Healthwatch are collecting personal data from an adult who may lack capacity to consent, where possible, people should be supported to allow them to make their own choices about how their personal data is used.

Consider whether there is another appropriate adult who can support the person or advise and/or agree that participating in our project is in the person's best interests (consultee). Consultees can be:

- A personal consultee (e.g. someone who cares for the adult lacking capacity but is not being paid such as friends and relatives)
- A nominated consultee (e.g. a professional such as care home staff)

People who need reasonable adjustments

Sometimes adults have capacity but will need additional support to read information and provide consent when personally identifiable information is being collected.

- Healthwatch should provide accessible information sheets and consent forms.
- Where it may be difficult to understand the person, it is important to find an interpreter to clearly convey the person's consent.

For example, these steps can be taken when Healthwatch collect feedback from:

- A member of the community, whose first language is not English;
- People with hearing impairments;
- People with learning difficulties.

Healthwatch should be aware that family/friends can act as interpreters, but a degree of consideration should be used. Healthwatch should be sensitive to the fact that someone may not want to disclose their information in the presence of family/friends. However, this should be considered on an individual basis and Healthwatch should be prepared to offer an alternative where appropriate (e.g. if the person appears uncomfortable).

Children and Young people

There are specific details to consider when processing children's personal data.

- Young people aged 13 years and above can usually give their own informed consent about how their data is managed in the same way as an adult, unless they are considered to not be competent to do so.

- If a child is under the age of 13 then you should usually obtain consent from a parent or guardian[1].
- If a child of any age is not able to decide for themselves, then their parent or guardian should provide consent on behalf of the child.

It is good practice to involve parents or guardians, even when a child or young person can provide informed consent, unless the young person objects.

People with mobility difficulties

It is good practice to collect a signature when obtaining consent. However, sometimes people may find it difficult to write and sign a document.

There are alternative ways to collect a signature, such as using:

- Online DocuSign tool
- A stamp
- A witness and the researcher to sign on their behalf

[1] https://ico.org.uk/for-organisations/guide-to-data-protection/key-data-protection-themes/children/