

Response to our consultation

Code of practice on confidential personal information

September 2016

The Care Quality Commission is the independent regulator of health and adult social care in England.

We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation.

Caring – treating everyone with dignity and respect.

Integrity – doing the right thing.

Teamwork – learning from each other to be the best we can

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Introduction

In 2010, the Care Quality Commission (CQC) published our Code of Practice on Confidential Personal Information. The Code established the practices that CQC follows to obtain, handle, use and disclose confidential personal information.

Access to confidential personal information plays an essential role in CQC's inspections and the wider regulation of health and social care services in England.

We review confidential personal information, including information from people's medical and care records, because it is a necessary way of helping us to understand the quality of their care and ensuring that we achieve our purpose of making sure people receive safe, effective, compassionate, high-quality care, and encouraging services to improve.

An important part of our regulatory function is to listen to the views of the public and people who use services, as their valuable experiences of care are vital in helping us to know when, where and what to inspect. But people need to feel safe when telling us about their care.

It is therefore vital that our Code of Practice is kept up to date and reflects current legislation, the changing sectors in which we operate, and recognised best practice. We also wanted to provide a clearer explanation of how we obtain, use, disclose and handle confidential personal information.

For these reasons, we produced a revised version of the Code and carried out a public consultation to seek people's views on it. We were keen to hear from people who may be affected by the practices set out in the Code – people who use the services that we regulate, their carers and families, and providers of care and their workers – as well as specialists and experts in the subject of information governance, and from across the health and social care sector.

In developing this Code, we have considered the Department of Health's [Confidentiality: NHS Code of Practice](#) and the [Code of Practice on Confidential Information](#) from the Health and Social Care Information Centre (now known as NHS Digital). We consider that our approach to confidential personal information, as set out in the revised Code, is consistent with these.

Our consultation

We consulted on our proposed revised Code of Practice on Confidential Personal Information to replace the previous version of the Code. This consultation ran from 30 November 2015 to 19 February 2016.

The revised Code does not propose substantial changes to CQC's current practice, but does differ from the original Code in a number of ways:

- It recognises changes in legislation, such as CQC's function of monitoring and reporting on providers' information governance practices, introduced under the Health and Social Care Act 2012.
- It references the HSCIC *Code of Practice on Confidential Information* and the *NHS Code of Practice on Confidentiality* and sets out the view that we consider the revised CQC Code to be consistent with these.
- It explains more clearly why the use of confidential personal information is vital to our role.
- It replaces the 'principles' in the original Code with a set of four 'practices' in relation to obtaining, using, disclosing/sharing, and handling confidential personal information. The previous use of the word 'principles' caused confusion with the Data Protection Principles and the Caldicott Principles, and they remain reflected in the practices set out in the Code.
- It adds specific examples to show how the Code translates into action.
- It recognises the introduction of Healthwatch England and the Freedom to Speak Up National Guardian.
- It provides an appendix with links to more detailed guidance and supporting documents. This is not part of the Code itself, so it will be easier to keep up to date.

We asked people to comment on the revised Code, and asked a set of questions to help us understand people's views on some key points. We also produced an easy to read version of the consultation document, to support as many people as possible in sharing their views with us.

When revising the Code, we were required by law to consult with NHS England (the operating name of the NHS Commissioning Board) and other appropriate people and organisations.

How we engaged and who we heard from

We promoted the consultation on our website, through our social media channels, and on our online community for providers and professionals (around 7,500 members) and the public (around 2,600 members).

We directly contacted 53 organisations to let them know about the consultation. We heard from a range of individuals and stakeholders throughout our consultation and accepted formal responses by email, by post and through the online form on our website. We received 39 responses through our website, which included:

- 11 health and social care professionals
- 4 providers of services
- 11 members of the public
- 4 recipients of healthcare and carers
- 5 voluntary and community sector representatives
- 3 stakeholders
- 1 member of CQC's staff.

We received a further eight responses on the easy to read version of the consultation form from people who use services.

We also received written responses from:

- 2 providers of services
- 6 voluntary and community sector representatives
- 8 stakeholders, including NHS England.

A list of the organisations that responded to this consultation is in the [appendix](#).

Not all respondents answered all of the questions. Some of the written responses made general comments, which we have mapped to the consultation questions for this report.

We would like to extend our sincere thanks to everyone who took the time to consider and respond to this consultation. All of the responses were carefully considered and were very helpful to us in developing the Code of practice.

We would also like to thank former members of CQC's National Information Governance Board who provided comments on an earlier draft of the Code of Practice, and therefore helped us in developing the version that was used for the consultation.

What you told us and our response

Consultation question 1

The Code explains the 'necessity test' that CQC uses whenever we have to make a decision about whether we need to obtain, use or disclose confidential personal information.

- Have we explained the 'necessity test' properly?
- Do you think that there are other things that we should take into consideration when deciding whether we need to obtain, use or disclose confidential personal information?

What you said

Most respondents thought that the 'necessity test' was well explained in the revised Code (37 said 'yes', seven said 'no').

A number of the concerns raised were about how CQC would involve people in decisions. Although the overall number of responses from individuals was very low, it was clear from these responses that some people have understandable concerns about CQC (and other regulators and organisations that are not directly involved in their care) having access to their information.

The Information Commissioner's Office (ICO) told us that it was important to be clear that decisions regarding accessing, using, holding and sharing confidential personal information must always be made in accordance with the Data Protection Act 1998. The British Medical Association (BMA) also wanted the Code to make it very clear that there needs to be a clear legal basis for processing confidential personal information.

The draft Code said that, wherever possible, we would involve parents or guardians in decisions about confidential personal information that relate to children. One concern suggested that there may be circumstances (for example, in relation to information about sexuality) where this may be against the wishes and/or interests of the child. NHS England suggested that we should clarify that we would not share information about a competent child with a parent or guardian without their consent.

Our response

To emphasise that there must be a lawful basis to any decision relating to confidential personal information, we have moved references to the Data Protection Act 1998 and the requirements of the Human Rights Act 1998 out of the footnote and back into the main explanation of the 'necessity test'.

We also made a stronger statement regarding our responsibility to notify people where we are making decisions about their confidential personal information. The draft Code referred to doing this where it was 'practicable', so we have therefore changed the wording to say that we will do this unless doing so would require a 'significant and disproportionate effort' and we added examples of how we would make this decision, to help to explain.

We have added a section to the revised Code that tells people how they can express a preference for CQC not to obtain and use their information.

We have also made it clearer that we would not share information about a competent child with a parent or guardian without their consent. We added a caveat to recognise that sometimes there may be exceptional circumstances in which it would not be appropriate to involve parents or guardians when making decisions about information relating to a child.

Consultation question 2

The Code explains how CQC uses its statutory powers to obtain confidential personal information, including medical records and personal care records, and how it may obtain confidential personal information in other ways.

- Have we explained this process properly in the Code?
- Do you think that the way we do this is fair?

What you said

The majority of respondents indicated that they thought CQC's process for accessing confidential personal information was well explained in the Code (35 said 'yes', seven said 'no'). Most also agreed that the approach was fair, although this was more balanced (30 said 'yes' it is fair, 16 said 'no').

Concerns were raised about how and when CQC would notify people when their records are being, or had been, accessed. Other comments highlighted the need to maintain the confidentiality of records, and that if a person has objected to their records being accessed for any other reason than providing their direct care, the reasons for CQC doing so would have to be very important. The Royal College of General Practitioners (RCGP) asked the question: how could people object and have their views considered and respected in cases where they don't know that CQC intends to access their records? For this reason, RCGP suggested that a person using services (or their representative) should always be notified where CQC has decided to access their records.

Our response

CQC considers that accessing confidential personal information (including medical and care records) during inspections is a necessary way of helping us to understand the quality of people's care and ensuring that we achieve our purpose of making sure people receive safe, effective, compassionate, high-quality care, and encouraging services to improve. Our inspectors will often not know what information we will need to look at before an inspection and, while we will access and use anonymised data wherever possible, there is a range of situations in which we need to have access to confidential personal information to carry out our role. In individual cases, it may be difficult and time consuming to identify, locate and effectively communicate with people whose information we wish to access. To do this in every case across all the inspections we conduct would add a significant amount of time and cost to our work, and would severely affect our ability to operate as an effective regulator.

Dame Fiona Caldicott's recently published [Review of Data Security, Consent and Opt Outs](#) highlights the wider need to raise awareness of the various ways in which information about people who use health and social care is accessed and used for 'secondary purposes' (purposes other than their direct care). These secondary purposes include access to confidential personal information by CQC and other statutory bodies and professional regulators as part of the running and monitoring of the health and social care system, among others.

We will consider what further steps CQC can take, both as part of a whole-system approach as proposed by Dame Fiona and as an individual organisation, to raise awareness so that people who use health and social care services can understand CQC's powers and express their views. The ICO told us that it is "important that providers whose records CQC may access also inform individuals that their records may be accessed by CQC". We have referred to this in the Code and will consider what further steps we can take to help providers to meet this Data Protection responsibility of their own.

We already publish a range of information about how we access and use confidential personal information (including the guidance listed in the appendix to the Code), and we will continue to develop and produce further information for people who use the services that we regulate.

We also added an example to illustrate our processes, where a CQC inspector decides that it isn't necessary to access confidential personal information and uses anonymised data instead. Another example shows where the inspector recognises where they didn't need to access the whole of a person's record for their inspection.

Consultation question 3

We have explained the different ways in which CQC uses confidential personal information to help us carry out our regulatory work, for example using care records to make judgements about care services.

- Have we explained this process properly in the Code?
- Do you understand how this information helps us in our work?

What you said

The majority of responses thought that CQC's use of confidential personal information in different circumstances were well explained in the Code (35 said 'yes', six said 'no'). The responses indicated that people understood how this information helps us in our work (37 said 'yes', seven said 'no').

Consultation question 4

We have explained how CQC handles and stores confidential personal information, keeps it safe, and disposes of it securely when it is no longer needed.

- Have we clearly explained how we handle confidential personal information in the Code?
- Are there any information security issues that we have not included in the report, or where we should be doing more to protect information?

What you said

The majority of responses indicated that we had clearly explained how we handle confidential personal information (31 said 'yes', seven said 'no').

The Health and Social Care Information Centre commented on the distinction between 'logical' disposal (for example, deleting data from a system) and physical destruction (such as destroying or securely overwriting a server). They suggested that the Code should make clear the need to ensure that deleted data cannot be retrieved – for example, by destroying old IT equipment.

We were asked to make clear that our rules on secure handling of confidential personal information do not only apply to CQC staff, but also to anyone else who handles the data on our behalf. NHS England suggested that we should state that the only people who would handle confidential personal information would be trained personnel with a legitimate need to access it.

We were asked to provide more information on how long we keep confidential personal information, how we handle any information security incidents or breaches, and whether we would tell someone if there was an incident involving their own personal information.

We were also asked if we assess ourselves using the Department of Health's Information Governance Toolkit.

Our response

We added further information to make clear that when we carry out 'logical' disposal of electronic data, we will always follow this up so that the destruction is irreversible. Also, we made clear that anyone handling confidential personal information on our behalf must meet the same confidentiality and security standards as we do. We now emphasise that only trained personnel with a legitimate need for access would handle confidential personal information.

We also added a reference to our information security incident processes and to our 'retention schedules'.

As with all issues relating to confidential personal information, the Code provides a general explanation of our practices. This is supported by much more detailed policies and guidance, which are available through weblinks in the appendix to the Code.

We now state in the Code that we are assessed annually using the Department of Health's Information Governance Toolkit and the report of the assessment is published on the Toolkit webpage.

Consultation question 5

Sometimes, CQC needs to disclose confidential personal information to other organisations to protect people from harm or unsafe care.

- Have we explained how we make decisions to disclose information properly in the Code?
- Do you feel that the decision-making process for disclosing confidential personal information is fair and appropriate?

What you said

Again, the majority of responses indicated that we had clearly explained how we make decisions to disclose confidential personal information (28 said 'yes', 12 said 'no'). The majority also thought that the decision making process was fair and appropriate (30 said 'yes', 10 said 'no').

The National AIDS Trust recommended that the Code should be consistent with GMC guidance in saying that we would only share confidential personal information obtained from medical records with the police in the most serious of cases, such as murder, rape or manslaughter.

The LGB&T Partnership and LGBT Foundation identified that disclosures permitted under the Health and Social Care Act 2008 and the Data Protection Act 1998 may still require further consideration if they contain 'protected information' under the Gender Recognition Act 2004.

Other respondents made clear their view that CQC should respect individuals' choices when making decisions on disclosure.

Our response

Consideration of the sensitivity of information is already part of the decision making process under the necessity test. But to highlight this, we have added an example to show that information from medical records would only be disclosed in relation to the most serious crimes. We have also added a statement to recognise that there may be additional legal barriers to disclosure, and a footnote giving the Gender Recognition Act as an example of this.

We have added a paragraph to reflect that, as part of considering the 'necessity test', we would not usually share or disclose confidential personal information where we are aware that the person to whom it relates has expressed a wish that it should not be shared for reasons other than their direct care, and that we would only do this in exceptional circumstances.

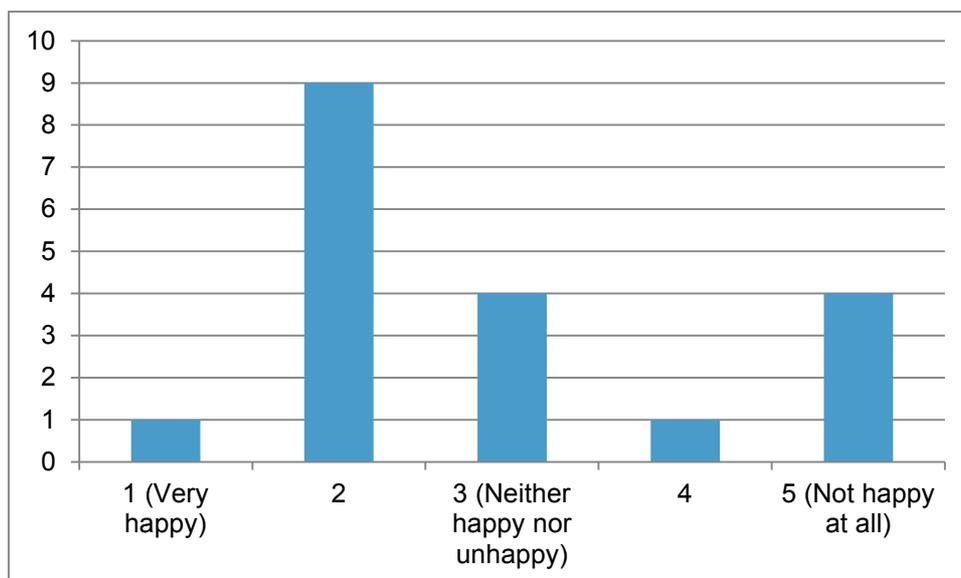
Consultation question 6

Having read the Code, how happy would you be for CQC to hold confidential personal information about yourself or members of your family?

- Please rate your choice on a scale of 1 to 5 (with 1 being very happy and 5 not happy at all)

What you said

Over half of the respondents to this question indicated that they were very happy or happy for CQC to hold their confidential personal information. However, five out of 19 gave a rating of 4 or 5, indicating that they were unhappy or very unhappy.



Our response

Although there was a relatively low number of responses from people who use services, carers and members of the public, and responses were overall in favour of CQC's approach, we recognise and understand the concerns that people have expressed about confidentiality and the potential for CQC's actions to impact upon their privacy.

We are also mindful of the recent report of the review of data security, consent and opt-outs by the National Data Guardian, Dame Fiona Caldicott. Dame Fiona has recommended a more robust approach for the NHS in understanding and acting on people's preferences in relation to sharing and using their information.

In the report, Dame Fiona recognises that there are some legal basis where the right to opt out may not apply. CQC's powers are an example of this.

We were given our powers by the public's representatives in Parliament and we have a statutory responsibility to use them to carry out our functions effectively and efficiently. However, CQC and our staff, representatives and agents are subject to a strict duty of confidentiality. We are therefore very aware that we must use our powers carefully. The revised Code renews our commitment to be mindful of people's wishes in relation to their own information and to respect those wishes as far as we are able.

We are also committed to transparency and openness about how we access and use information. Publication of the revised Code and supporting guidance are a step towards meeting that commitment. But we will work to provide more and clearer information through our own actions and publications, and by helping providers of care and other organisations to explain how and why CQC needs to obtain, use, handle and disclose confidential personal information.

Further information

We have now revised the draft Code that was the basis of this consultation to reflect the feedback, and it is published on our website.

We will continue to keep the Code under review and develop the underpinning policies, processes and guidance.

We welcome feedback on all these documents, and on our practices. You can contact us at our National Customer Service Centre in Newcastle:

Telephone: 03000 616161

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Or write to us

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Appendix: Organisations that submitted responses

National charities

- Barnardo's
- Carers Trust
- LGBT Foundation
- National AIDS Trust
- Parkinson's UK

Professional representatives

- British Medical Association
- General Medical Council
- National Care Association
- Nursing and Midwifery Council
- Royal College of Anaesthetists
- Royal College of General Practitioners
- Royal College of Obstetricians and Gynaecologists
- Royal College of Pathologists
- Royal Pharmaceutical Society

Health and social care providers

- Bankfield House Care Home
- Frimley Health NHS Foundation Trust
- Oxford Health NHS Foundation Trust
- Oxford University Hospitals NHS Foundation Trust
- Ribble Care Limited
- South Essex Partnership University NHS Foundation Trust
- Sue Ryder
- Western Sussex Hospitals NHS Foundation Trust

Strategic partners

- Health and Social Care Information Centre (now NHS Digital)
- Information Commissioner's Office
- NHS England

Other groups

- Healthwatch Enfield
- Information Governance Alliance
- MedConfidential
- National LGB&T Partnership
- Patient Concern