

Code of practice on confidential information

Update following public consultation

Nicholas Oughtibridge

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Background

The Health and Social Care Information Centre (HSCIC) has a duty under section 263 of the Health and Social Care act to prepare and maintain a Code of Practice on confidential information (Code of Practice). In May this year Department of Health and NHS England were consulted and the HSCIC sought the views of the public and interested organisations through an open consultation. This consultation closed on 18 September.

The Code of Practice applies to organisations which provide information functions, that is they collect, analyse, publish or otherwise disseminate confidential information concerning or connected with health services or adult social care delivered in England.

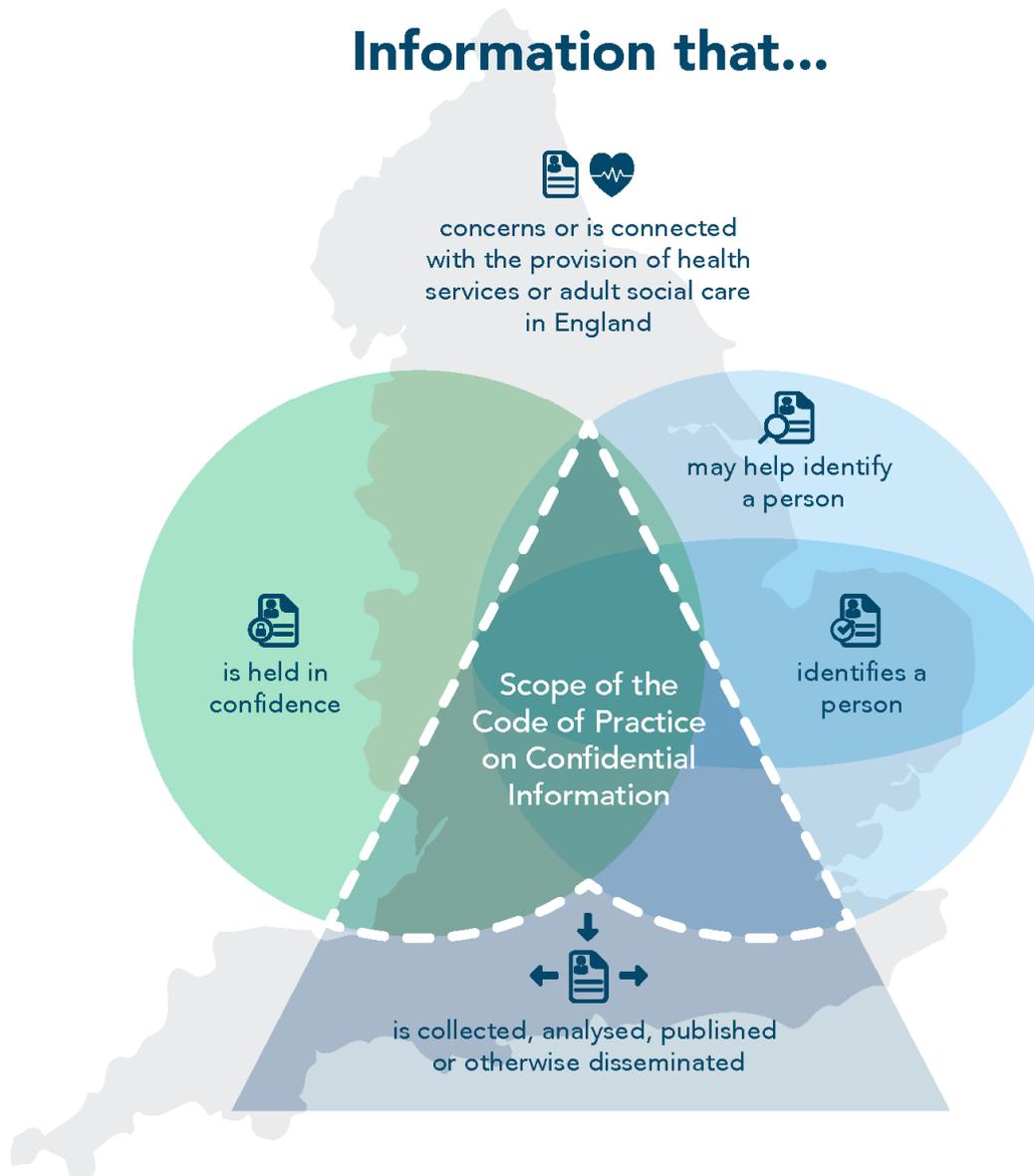


Figure 1 – illustration of the scope of the Code of Practice

The Code of Practice does not apply to the direct provision of care, related record keeping or documentation facilitating the handover of care from one care provider to another. In

September 2013 we published “A guide to confidentiality in health and social care¹” as guidance to support direct provision of care.

It does not extend to the HSCIC’s system delivery functions, that is the development or operation of information or communications systems in connection with the provision of health services or of adult social care.

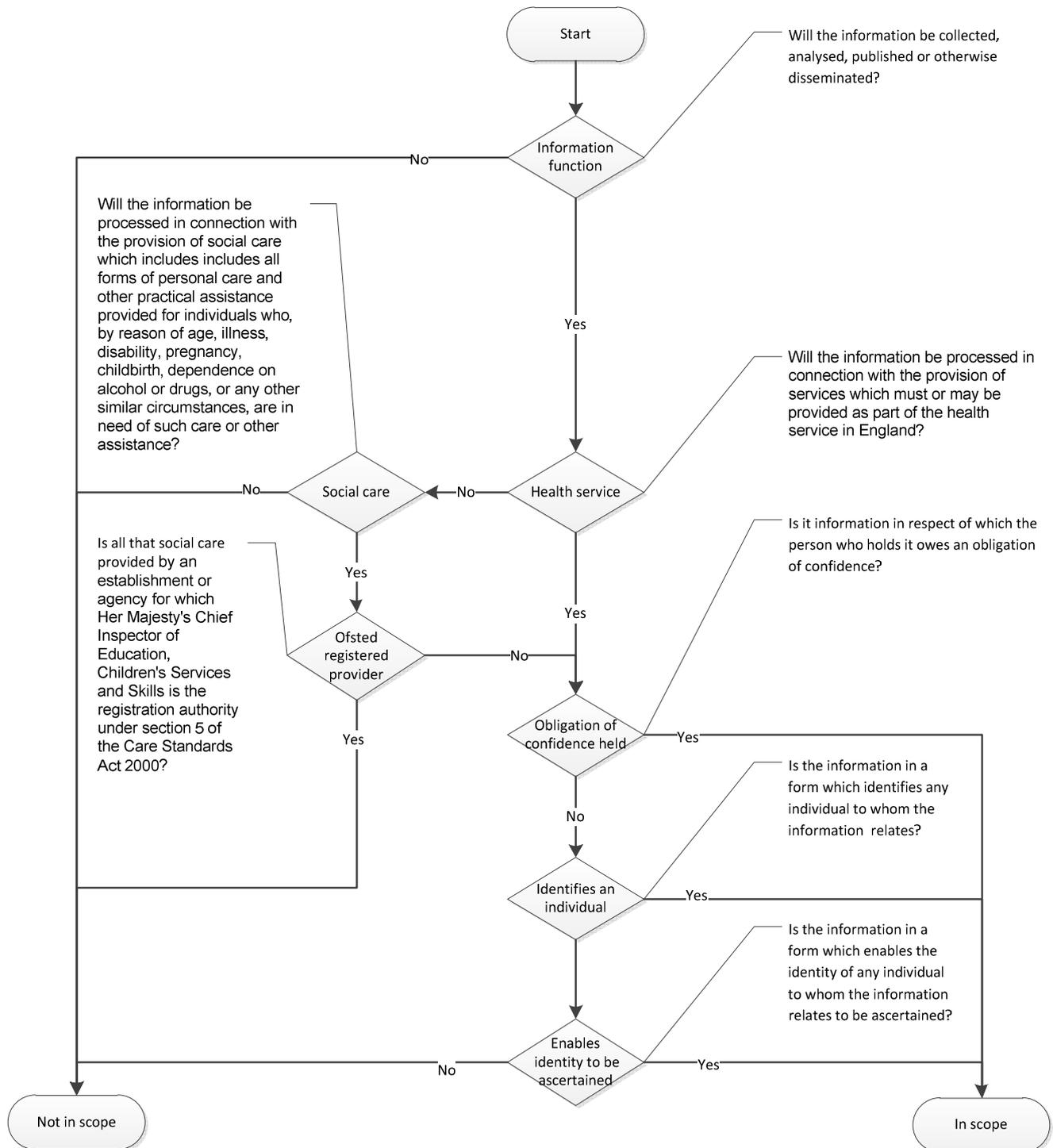


Figure 2 – Flow chart to assist interpreting the scope of the Code of Practice

¹ <http://www.hscic.gov.uk/confguideorg>

Section 263 – Health and Social Care Act 2012 – Code of practice on confidential information

(1) The Information Centre [HSCIC] must prepare and publish a code in respect of the practice to be followed in relation to the collection, analysis, publication and other dissemination of confidential information concerning, or connected with, the provision of health services or of adult social care in England.

(2) For the purposes of this section “confidential information” is—

- (a) information which is in a form which identifies any individual to whom the information relates or enables the identity of such an individual to be ascertained, or
- (b) any other information in respect of which the person who holds it owes an obligation of confidence.

(3) Before publishing the code, the Information Centre [HSCIC] must consult—

- (a) the Secretary of State,
- (b) the Board, and
- (c) such other persons as the Centre considers appropriate.

(4) The Information Centre [HSCIC] must not publish the code without the approval of—

- (a) the Secretary of State, and
- (b) the Board, so far as the code relates to information concerning, or connected with, the provision of NHS services.

(5) The Information Centre [HSCIC] must keep the code under review and may revise it as it considers appropriate (and a reference in this section to the code includes a reference to any revised code).

(6) A health or social care body must have regard to the code in exercising functions in connection with the provision of health services or of adult social care in England.

(7) A person, other than a public body, who provides health services, or adult social care in England, pursuant to arrangements made with a public body exercising functions in connection with the provision of such services or care must, in providing those services or that care, have regard to the code.

Commitment

In their submission to the Health Select Committee the Chair, Kingsley Manning and Director of Information and Analytics, Max Jones confirmed our intent to publish a draft Code of Practice on confidential information at the end of June 2014. This will be for consultation during the summer. Subject to feedback received following that consultation, the Code of Practice will then be adopted and published by the end of September 2014.

Progress to date

Despite Section 263(3) we have taken the decision to undertake a full public consultation on a draft of the Code of Practice. That consultation closed on 18 August 2014. The submissions received have proved invaluable. The feedback received from the consultation is requiring discussions with Department of Health (DH) officers as part of our ongoing consultation with DH.

The volume and detail of the feedback given by the public has meant that it has not been possible to provide the Board with a final text for this meeting.

Feedback from the consultation

We received 71 responses through the consultation on CitizenSpace. Of those:

- 21 responses were from patients / service users or citizens.
- 54 respondents rated their current understanding of information governance as good or excellent. Only two rated it as poor or very poor. The remaining 15 rated their understanding as satisfactory. 20 respondents said their understanding had improved by reading the Code of Practice; Seven respondents stated their understanding was not improved by reading the Code of Practice.
- 41 respondents reported that the Code of Practice was clear; eight disagreed.
- 43 stated there is conflicting guidance or greater clarity is required. The topics identified included
 - proposals for accredited safe havens,
 - the scope defined in S263 of the Health and Social Care Act 2012 is not aligned with other legislation,
 - requests to include childrens' social care
 - the handling of objections,
 - pseudonymisation,
 - request for an explanation of S251 of the National Health Service Act 2006,
 - joint data controllers are not discussed
 - requests for specific advice around confidential information concerning sexually transmitted diseases
 - the section on objections does not set out the legal rights of individuals to object to processing under certain conditions,
 - absence of discussion of adoption records
 - no references to the Human Rights Act or the Freedom of Information Act
 - legal options that allow linkage
 - include the details of the standard burden calculation methodology

In addition we received 16 detailed written submissions from the Association of Medical Research Charities, British Association of Sexual Health and HIV, British Heart Foundation,

Dr Ben Goldacre and Síle Lane, Health Research Authority, Health Statistics User Group Committee, Independent Information Governance Oversight Panel, Information Commissioner's Office, medConfidential, Medical Research Council, National AIDS Trust, National Ambulance IG Group members, NHS England, UK Faculty of Public Health, Wellcome Trust and Yorkshire Ambulance Service.

Key issues raised in consultation

Legal

Since the draft Code of Practice was prepared the Care Act has been passed. This act, in section 122, places additional restrictions on the HSCIC in relation to dissemination of information. A number of respondents requested the Code of Practice be updated to reflect Section 122.

The DH have given firm advice that the Code of Practice should be limited to the HSCIC information functions and to equivalent information functions provided by other bodies. These functions will, in some cases, be provided by Accredited Safe Havens. Alignment with the anticipated regulations concerning Accredited Safe Havens is requested by several respondents including the Independent Information Governance Oversight Panel (IIGOP). This dependency may delay the publication of the Code of Practice.

IIGOP recommended the addition of a section describing the requirements of law and additional explanation of how legal underpinnings interreact. This is being incorporated into the revised introduction and the body of the Code of Practice.

NHS England suggested the section requiring the establishment of the purpose of arrangements to handle confidential information include a requirement to establish the legal basis for that handling.

The Information Commissioners Office raised concerns that organisations may see the Code of Practice as a complete approach to managing personal health information, and requested that reference to the Data Protection Act requirements are made clearer.

The Health Research Authority expressed concerns regarding the broad definition of Confidential Information in the Code, specifically how it is interpreted in line with other statutory obligations and common law.

Scope

Many respondents had difficulty understanding the scope of the Code of Practice. The scope is being rewritten including the development of the illustrative diagram at figure 1 above.

The DH note that the Code of Practice on confidential information does not apply to system delivery functions. It is not always evident whether a direction from DH is to establish a system for the collection or analysis of information under section 254 of the Health and Social Care Act or to exercise system delivery functions under Section 274(d) of that act.

IIGOP also recommended the scope be clearer on the scope for interpretation when the intended audience (Board members) cascade this down to staff. The Code of Practice is intended for top management; we intend to prepare separate publications in collaboration with the Information Governance Alliance.

NHS England requested the Code of Practice make it clear that it is limited to health services or adult social care. Health services are services which must or may be provided as part of

the health service in England. Health services do not include privately funded health care which is not provided as part of the health service. The introduction is being updated to make this clear.

Many respondents were concerned that the scope of the Code of Practice excluded children's social care, that is social care provided by an Ofsted regulated body. The introduction is being amended to explain the legal background to this aspect of the scope.

NHS England suggested the Code of Practice highlight additional practices required for confidential information that does not relate to an individual, such as contractual information or intellectual property.

Objections

A significant number of people requested that the HSCIC describe the practices for recording, collecting, sharing and respecting people's objections to the processing of their information. There are three bases for people's rights to object:

- There is a general right leading from Article 8 of Human Rights Act to have objections to the processing of personal information considered.
- There is a specific right in section 10 of the data protection act where processing would lead to unwarranted substantial damage or substantial distress
- During the consultation period for the draft Code of Practice the policy became that an expressed objection should be presumed to be reasonable.

Understanding of the best practice to follow for recording, collecting, sharing and respecting people's objections to the processing of their information is under-developed. The Code of Practice does not, therefore, describe a best practice. The Code of Practice will be reviewed regularly with a view to describe practice once best practice has been identified.

The policy does not apply where a specific direction requires the HSCIC to process confidential information.

Management systems

The London Caldicott Guardian Forum requested that there be an explicit reference to the role of the Caldicott Guardian.

The DH noted that the information governance toolkit contains required practices for management systems. They note that the Code of Practice should include specific practices, not simply refer to other sources of practice such as the IG toolkit.

Analysis

NHS England also requested more practices covering cleansing, linking, derivation of confidential information and calculations from confidential information.

An academic team studying linkage errors recommended a practice to consider holding and processing confidential information in a trusted third party safe processing area such as the HSCIC or an accredited safe haven, a closed system or adopting pseudonymisation at landing.

Research

A number of respondents were concerned that the Code of Practice applied to personal information where there is a minimal risk of reidentification of the person. The Code of

Practice is limited to the definition of confidential information in section 263 of the Health and Social Care Act 2012 which includes information which enables the identity of the individual to be ascertained. Consequently, no change is proposed.

A private respondent recommended that the analysis strategy be determined at the time of establishing the purpose of the information collection.

A number of respondents requested that consideration be given to the open access research sharing standards. Policy advice is being sought from the DH on this matter.

A number of respondents were concerned that the Code of Practice may be seen as a barrier to legitimate research. This is not the intent of the Code of Practice.

Data release register

medConfidential requested that the Code of Practice require a data release register and that each organisation's data release register includes the legal basis for sharing confidential information. The HSCIC already publishes such a data release register².

Adoption approach

Internal

We have already engaged staff as part of the wider consultation. Over 5% of staff have contributed through briefing discussions. We will cascade briefings to staff once the Code of Practice has been published. We will focus on key areas and roles, including:

- Information Asset Owners and assistants
- Data and Information services
- Staff handling Personal Confidential Information
- The system delivery functions

External

There are three options for supporting adoption by external bodies

1. Take no action
2. Provide guidance through documents, interactive education tools and videos
3. A direct programme to promote adoption

It is intended that the Health and Social Care Information Centre adopt option two, that is provide guidance through documents, interactive education tools and videos. This enables the value of the Code of Practice to be realised without assuming accountability for its adoption in relevant organisations.

² <http://www.hscic.gov.uk/dataregister>

Approach to approval and publication

The strong advice from significant stakeholders is that the Code of Practice should be aligned with the regulations concerning accredited safe havens. There are two approaches to approval and publication offered.

Publish in September and revise shortly after

- The Code of Practice is finalised without sight of the regulations for accredited safe havens
- The Code of Practice is approved on behalf of the HSCIC by Chair's action including two non-executive directors, Andy Williams, Rob Shaw and Martin Severs (as Caldicott Guardian).

Publish with alignment to the imminent regulations concerning accredited safe havens

- It is recommended that the Code of Practice is considered at the Board meeting following publication of and alignment with the regulations on accredited safe havens.

Recommendation

The recommendation is to publish with alignment to the imminent regulations concerning accredited safe havens.

In addition to approval by the Health and Social Care Information Centre, the Code of Practice needs approval from the Department of Health and NHS England.

Actions Required of the Board

To note the progress to date and the nature of feedback received.

To agree the approach to approval and publication.