

Dissemination of Civil Registrations Data

Consultation with the Confidentiality Advisory Group

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1 Executive Summary

NHS Digital is working with the Office for National Statistics (ONS) and General Registrars Office (GRO) to confirm NHS Digital data controllership of the Civil Registrations Births and Deaths data which is currently holds. This will mean that in future we will no longer be reliant on the Statistics and Registration Service Act 2007 (SRSA) legal gateways and the other SRSA requirements.

Civil Registrations Data will now be disseminated to applicants under NHS Digital legal gateways under the Health and Social Care Act 2012 and, as such, there is now the opportunity to reconsider the application of duties of confidence to the data once NHS Digital Data Controllership is confirmed.

2 Purpose

This paper sets out NHS Digital's suggested policy position and is seeking CAG's opinion firstly as to whether there should be any change in consideration of duty of confidence, in particular to Date of Death, and secondly the practical implications of the change in legal gateways on existing and future section 251 applications to CAG.

3 Background

Since late 2013 patients have been able to register an opt-out to NHS Digital sharing their confidential patient information for purposes beyond their direct care, referred to as a type 2 opt-out and NHS Digital consider type 2 opt alongside any considerations in relation to duty of confidence when disseminating data. A Direction was issued in April 2016 to enable implementation of type 2 opt-outs which set out the policy position for when opt-outs should and should not be applied.

A policy was developed around the legal basis for accessing and using data but the Direction was silent on the Statistics and Registration Services Act (SRSA) legal gateways. NHS Digital currently relies on the SRSA when we disseminate ONS mortality data (most notably fact of death, Date of Death and cause of death) which is often, but not always, released alongside our own data. Mortality data is key for many purposes including clinical audit, medical research, assessing quality and safety and for regulation.

Other key considerations are:

- Although the Data Protection Act only applies to living persons the common law duty of confidence does extend to dead persons. NHS Digital has also agreed a policy position that the application of type 2 opt-out would continue following a person's death¹
- opt-outs apply only to data considered to be confidential patient information² which is defined as :
 - identifiable or likely identifiable,
 - about an individual's health, care or treatment, and
 - given in a situation where the individual would expect the data to remain private i.e. the information is not in the public domain or common knowledge³.

¹ in line with Department of Health and the General Medical Council agreed ethical position.

² as defined in section 251 (11) of the NHS Act 2006.

³ However any data flowing using Section 251 as the legal basis is automatically considered to be confidential patient information.

- Mortality data (taken from General Register Office [GRO] data) is not considered to be owed a duty of confidence as it is drawn from a public register.
- Under SRSA Date of Death is considered to be “personal information”; NHS Digital considered that this meant that a person’s identity is directly specified in the information and applied type 2 opt outs. The SRSA consideration will no longer apply and data will be released under NHS Digital legal gateways.

4 Consultation

4.1 Date of Death - released with anonymised health data (ie compliant with the ICO anonymisation code of practice)

Key to taking decisions on the application of the ICO anonymisation code of practice is a determination as to whether data are identifiable and further to this whether the data are considered as direct identifiers or indirect identifiers.

Direct identifiers being a single data item from which a person can be identified e.g. a name and therefore this data item must be removed, pseudonymised or turned into some form of derived data item instead. An indirect identifier being any data item which in combination with other identifiers might make the data identifiable so largely any data about the characteristics of an individual such as ethnicity, title, occupation, wider geographical indicator such as Lower Super Output Area. The ICO Code of Practice allows for the data controller to assess the risk of re-identification and to continue to flow indirect identifiers where there are wider controls e.g. security controls and contractual penalties. Consideration is given as part of the dissemination process that decide whether such data item can/will be provided in the clear or need to be derived.

Currently Date of death is considered under SRSA as personal information which means it must be considered identifiable. When ONS Mortality data is released with a pseudonym that it enables it to be linked to a data set (A) also with the same pseudonym then data set (A) becomes identifiable and therefore considering the entirety of the data being released then type 2 opt-outs must be applied. Indeed as a general rule the type 2 opt-out will be applied to both data files (ONS data and health data) as well.

With the removal of the SRSA legal gateways Date of Death will no longer have an SRSA classification of personal information it is proposed to classify Date of Death as an indirect identifier.

4.2 Impact Assessment

It is recognised that there are implications for customers arising from any decision to apply duty of confidence and type 2 opts to Date of Death. For some purposes Date of Death can be derived to mm/yy or replaced by age at death and this data could continue to flow in full with other health data in compliance with the ICO anonymisation code of practice. But we do know that exact Date of Death is essential for some purposes e.g. in assessing 30 or 60 day mortality rates following a specific episode or treatment. Therefore the application of the type 2 opt-out means that customers are receiving data which has had a proportion of patient records removed – unless they can apply for identifiable health data under a legal basis that does not require the application of type 2 opt-outs. It is worth noting however that for most medical research where data are released under Section 251 this will mean that Type 2s are upheld.

It should be noted that within Caldicott 2 “Information to share or not to share” Date of Death is listed as a direct identifier. However, it is important to consider this issue in the wider context of the NDG review and the broader drive to increase the use of anonymised data as well as to fully assess the options, risks and benefits of flowing exact Date of Death as part of a release that is anonymised in line with the ICO code of practice.

NHS Digital is seeking CAG’s opinion generally upon whether Date of Death should continue to be considered a direct identifier or as an indirect identifier when disseminating health and social care data anonymised in line with the ICO anonymisation code of practice.

4.3 Section 251 and CAG Approval Letters

The practical implications of Civil Registration Data being under NHS Digital data controllership also require consideration. Whilst there is no material change to the Civil Registrations data set, the ONS Terms and Conditions, established by SRSA will no longer apply; for example Approved Researcher Status.

Currently mortality data is described as Civil Registrations Data or ONS Mortality Data in CAG Section 251 Applications or Approval Letters. Applicants will now be seeking to receive data from NHS Digital and mortality data will be released under NHS Digital legal gateways, therefore applications will no longer use the reference ONS Mortality Data/ONS Data. NHS Digital would consider the term ONS Mortality data to be acceptable on pre-existing Section 251 approvals, as there is no change to the data set covered in the application and it would consider it to be an unnecessary burden upon applicants to ask them to see an amendment to the Section 251 until such times as the application is reviewed. However, NHS Digital is seeking CAGs opinion on this position.

In addition, NHS Digital currently disseminates ONS death data alongside its own health data under the SRSA legal gateways, for example under Section 42(4) of the SRSA. This data would now be released under NHS Digital legal gateways therefore for certain studies a Section 251 may cite health related data items but not list date of death. NHS Digital is seeking CAGs opinion as to whether those existing studies should be requested to update their Section 251 to include date of death. This would be dependent upon CAGs opinion above as to whether date of death should be treated as a direct identifier or not.

5 Next Steps

NHS Digital is seeking CAG’s opinion as to whether there should be any change in consideration of duty of confidence to the data set, in particular to Date of Death.

- With the removal of the SRSA legal gateway and ONS Terms and Conditions should Date of Death continue to be considered as a direct identifier or as an indirect identifier?
 - NHS Digital’s preferred position and recommendation is that Date of Death be considered as an indirect identifier
- Subject to the answer above; should Date of Death continue to be considered a direct identifier or indirect identifier in relation to data released in line with ICO anonymisation code of practice?
 - NHS Digital’s preferred position and recommendation is as that given above.

- Subject to the answers given to the above questions; given that there is a change in data controllership for data released for the purposes of health and social care research but no change in the civil registration data set is there any impact upon existing Section 251 approvals which include the mortality data set?
 - NHS Digital is seeking CAG's position on this matter; it would however seek to reduce the burdens placed upon researchers as much as practicable. NHS Digital would therefore recommend that should CAG consider that existing Section 251's require updating to include date of death, NHS Digital provide CAG with a list of current research studies with a Section 251 approval who also currently receive date of death under the legal basis of s42(4) of SRSA. NHS Digital suggest that a special condition is agreed to accept that date of death be included in the Section 251 for those studies until such times as it is reviewed by CAG.