



Health Research Authority

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NHS Digital Advice request (2) to the HRA Confidentiality Advisory Group

Advice request: Change in data controllership of births and deaths Civil Registration Data for Health & Social Care research purposes

Advice request summary:

This advice request was considered by the CAG at its meeting on 12 October 2017.

The introductory letter confirmed that NHS Digital is working with the Office for National Statistics (ONS) and General Registrar's Office (GRO) to confirm NHS Digital data controllership of the Civil Registrations Births and Deaths data which it holds. This will mean that in future NHS Digital will no longer be reliant on the Statistics and Registration Service Act 2007 (SRSA) legal gateways and the other SRSA requirements for the dissemination of births and deaths civil registrations data.

The position NHS Digital has reached was submitted in a supplementary paper which sets out the draft policy position. In addition, advice was sought on three specific aspects:

1. With the removal of the SRSA legal gateways and ONS Terms and Conditions should Date of Death continue to be considered as a direct identifier or as an indirect identifier?
2. Should Date of Death continue to be considered a direct identifier or as an indirect identifier in relation to data released in line with ICO Anonymisation Code of Practice?
3. 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?

Confidentiality Advisory Group advice to NHS Digital

Members welcomed the attendance via teleconference of Professor Martin Severs and Ms Joanna Treddenick, and found the discussion helpful in providing necessary context and background to the submitted information. The following presents a high-level summary of the CAG discussions.

- It was explained that the overarching purpose was part of a broader piece of work to seek to improve data sharing and unnecessary burdens upon researcher access, and was linked to a broader programme of work led by the Research Advisory Group.
- Members questioned why the focus was on mortality data, although birth data was technically included, and it was explained that access to mortality was a key issue for researchers; and while often this could be pseudonymised often researchers required access to full date of death in order to establish 30 and 60 day mortality.
- It was confirmed that Directions were already in place to effect this change, however, a transition date had yet to be agreed, although an indication was that this was hoped to be the beginning of November 2017.
- Members expressed their understanding that Parliament, when debating the Statistics and Registration Services Act, had felt that date of death warranted specific mention as an identifier, in addition to the report *'Information: To Share or Not to Share? The Information Governance Review'* ('Caldicott 2').
- Members expressed some nervousness as to whether the change would involve a change in scrutiny that would follow as a consequence. It was noted that, with the proposed change in data controllership, if date of death is considered to always render a dataset identifiable, then disclosure under Regulation 5 of the COPI Regulations would include consideration by CAG. It was noted that if classified as an indirect identifier, that this could be perceived as a mechanism to avoid this independent level of scrutiny. NHS Digital explained that previous consultation had been undertaken with ONS and they had confirmed that date of death was assessed in terms of risk only when combined with additional datasets. NHS Digital confirmed that any such requests would in future be reviewed via the NHS Digital IGARD processes.
- Members questioned whether the proposed change would have an impact on the management of 'Type 2' objections. It was confirmed this will have an impact as if not considered identifiable, 'Type 2' objections would not need to be applied.
- It was confirmed that due to the standard conditions applied to supported applications under Regulation 5 of the COPI Regulations 2002 that this condition of support would continue to be upheld in relation to 'section 251' applications advised against by the CAG.

- Members questioned what the intentions were for a public explanation of the proposed changes. It was highlighted that in terms of maintaining public confidence in the appropriate handling and dissemination of information that there could be a risk this could be perceived as a loss of public control, and therefore it would be incumbent for NHS Digital to ensure that there are appropriate, proportionate and effective controls in place to mitigate against risks.
- Members also highlighted whether any discussions had been undertaken with the National Data Guardian. NHS Digital advised that it would be helpful to receive the CAG advice so they could report to the Research Advisory Group, and that they could return to the CAG after they had sought advice from the National Data Guardian.

CAG Advice conclusions

1. Members noted that considering the proposed transition date of early November 2017, the advice request appeared to have been submitted close to this date, and it would have been preferable if it had been submitted at a much earlier stage as members were aware that activity around this aspect had been progressing as part of the Research Advisory Group since March 2017. CAG noted that in order to ensure that its advice was robust and considered, sufficient time was required to consider and formulate its advice and this should be taken into account when submitting future advice requests. As such, where action prior to implementation is recommended, earlier engagement with the CAG would be recommended in future to help mitigate against any negative impact on implementation timescales.
2. CAG advised that work should be undertaken by NHS Digital to avoid potential negative public perceptions that the change could involve a perceived reduction of the current scrutiny involved regarding the disclosure of confidential patient information. CAG advised that:
 - a. This could potentially be achieved through ensuring there are equivalent and proportionate robust controls under the proposed new approach, as is in place for the existing approaches and processes.
 - b. There should be authentic public messages developed to explain how the controls are proportionate and appropriate and that there is no greater risk to patient confidentiality under the proposed new approach. Also, how the proposed approach is consistent with the assessment of identifiability within the system as a whole.
 - c. Any disclosures should be consistent with the Information Commissioner's Office Anonymisation Code of Practice.
3. CAG advised that NHS Digital should engage with the National Data Guardian, and should only proceed if she is content with the anticipated changes and transition arrangements, including the level of NHS Digital

scrutiny. It was advised the consultation with the National Data Guardian should include the following:

- a. The move to treating date of death from a direct to an indirect identifier as this was originally described as a direct identifier in 'Caldicott 2'.
- b. Whether the National Data Guardian is satisfied with the proposed public explanation of any change.
- c. Whether the shift remains effective and proportionate in terms of the risk factors involved, and any subsequent messages

The CAG hopes that you find the advice above helpful.

Publication of Advice request and CAG advice

Please be advised that the intention is to publish the CAG advice and underpinning advice request letter and consultation paper on the HRA website. If you have any issues regarding publication, please can you advise us via HRA.CAG@nhs.net. If no feedback is received within 10 working days, this will be understood to reflect that there are no issues and publication will take place in due course.

Yours sincerely

Dr Mark Taylor
CAG Chair