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IC-248082-T1C1

Request

You asked us:

"I am doing some work on the use of the NHS number beyond health/care and in education. Report after report including the Children's Commissioner has recommended the use of the NHS number in education, but apparently the ICO (c. 2016) took the view that this should not happen because of privacy concerns. Are you able to provide documentation on this ICO position and has it changed?"

We received your request on 19 July 2023. We have handled your request under the Freedom of Information Act 2000 (the FOIA).

Our response

In relation to the first point of your request concerning the policy position expressed in or around 2016, I can confirm we do hold some information in scope of your request.

The use of an NHS number as a consistent identifier is a longstanding matter. During my consultations with relevant teams, I have been advised that we clearly did set out a position on or around 2016 because it is alluded to in the Department for Education report 'Using a consistent identifier - education and children's services', which states:

"The Department for Health has given an undertaking to the Information Commissioner that the NHS number will be used for health and social care only, in response to the Information Commissioner's concerns about the NHS number being used for other purposes"

With this in mind, I set out to try and find if we still hold information about that position. Given that it was so long ago, I expected that much of it would be deleted in line with our retention periods. Nevertheless, I did manage to find



some historic information stored in a legacy system, which I will quote the relevant excerpts of below.

Before I do so, I must emphasise that since the below information was created, we have undergone several changes of Commissioner, who may have different views on this matter, as well as a legislative change following the introduction of the GDPR and the DPA 2018. Therefore, while this is provided because it is in scope of your request, given its age the advice should be treated as a historical record rather than implying a current position.

From a 2003 document titled "NHS number and the EC data protection directive", we hold the following relevant information:

"Restrictions on the use of the NHS number (whether prescribed by order, or in policy)

The Commissioner's position is that an identifier such as the NHS number should only be used in the context in which it was created, unless a strong business case could be made for using it in other situations. Paper HRDG 23/2003 proposed the following as a policy statement for use of the NHS number:

"The NHS number is an administrative identifier created and owned by the Secretary of State for Health to enable the reliable linkage of healthcare records held by health service bodies".

The Commissioner would not be opposed to the NHS number being used by a non-healthcare body as a means of linking its records with the healthcare records held by a health service body, where this is necessary because both bodies are working together to deliver a joint service. An example of such joint working would be in the provision of mental health services e.g. by both a health body and a social services body. For the purpose of delivering such a service, the Commissioner would not be opposed to the NHS number being used by the organisations involved as a means of linking records. There may, of course, be other examples of joint working involving a health service body and a non-health service body where the same position can be taken.

[NB: In previous discussions on this issue within the HRDG, it was suggested that the Sure Start programme (involving health, social services and education) may be another example of a joint service where the NHS number could be used for record linkage. After further discussion within the Office on this particular example, it is the Commissioner's view that use of the NHS number is unlikely to be appropriate in this situation. This is because the Sure Start programme is not



directly health-related, rather it is to promote the overall development of disadvantaged young children with a view to tackling poverty and social exclusion.]

The Commissioner would be opposed to the NHS number subsequently being used by a non-health service body for purposes not related to the service it was providing jointly with the health service body. For example, where an NHS number is in the possession of a social; services body that has been providing joint mental health services, it should not then be used as a unique identifier by the social services body for the individual as he or she receives other services from the social services body that are not health related.

Why should the NHS number only be used in the context in which it was created?

There are two Data Protection Principles that are likely to be breached if the NHS number is used outside of the context in which it was created (and where there is no strong argument for that additional use).

The Second Principle requires that personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes. It would be incompatible for a non-health service body to further process the NHS number beyond the processing that was necessary for record linkage while providing a joint service with a health service body.

The Third Principle requires that personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which it is processed. While it would be relevant for a non-health service body to process the NHS number for the purpose of record linkage while providing a joint service with a health service body, it would not be relevant to process the NHS number for other purposes where it is not necessary to link records with those of a health service body. The processing of the NHS number in these circumstances would be excessive for the purpose.

A further concern relating to any widespread use of the NHS number outside of the context in which it was created is in respect of the requirements of the Seventh Principle. This requires that appropriate technical and organisational measures are taken to ensure the security of personal data. The widespread use of the NHS number in non-health situations may increase the risk of the NHS number being used in identity fraud. This may result in individuals receiving healthcare to which they are not entitled (resulting in an additional cost to the



NHS), or being able to access personal data to which they are not entitled (resulting in a breach of confidentiality, and potentially a cost to the NHS)."

On 1 September 2015, we received an email from the NHS thanking us for providing input on a paper. One comment recorded confirms our position at the time, and reads:

"Worth reiterating here so there is no confusion that the nhs numbe can only be used where necessary and only for health and care purposes."

On 24 June 2016, we created a 'line to take' document. These documents detail how we as an organisation should respond when we receive enquiries about a particular topic. The document detailed our position about use of NHS numbers. I have attached it.

I have been unable to locate any further relevant information detailing this historic policy position.

In relation to current position, there is very limited information in scope of your request. In a meeting note dated 22 March 2022 between the ICO and the Office of the Children's Commissioner, we noted:

"Things have changed a lot since ICO gave last advice on UI and data sharing in 2015, and ICO is now much keener to push data sharing."

For context, this comment was made within the knowledge of the ICO having undertaken a lot of work on <u>data sharing</u>, including for example our <u>Data Sharing</u> <u>Code of Practice</u> which provides practical advice for organisations about how to share personal data in a lawfully, fairly, and proportionally.

Additionally, in an internal email dated 16 May 2023 about the Department for Education report on 'Improving multi-agency information sharing', we noted:

"We haven't provided a position on the specific issue of the use of the NHS number as a CCI... We will keep you updated with any developments, but wanted to make you aware of the request and to see if anyone had a steer on what action the ICO should take, ie. if we should form a policy position or not."

You will note from this that presently we do not have a policy position on this issue, however this is owing to the recent re-emergence and currency of the issue. The ICO will review the proposed policy and its implications under UK GDPR/DPA 2018 when we have more information on the proposal.



I have been unable to locate any further information about our current policy position besides the above.

This concludes our response to your request.

Next steps

You can ask us to review our response. Please let us know in writing if you want us to carry out a review. Please do so within 40 working days.

You can read a copy of our full review procedure <u>here</u>.

If we perform a review but you are still dissatisfied, you can complain to the ICO as regulator of the FOIA. This complaint will be handled just like a complaint made to the ICO about any other public authority.

You can raise a complaint through our website.

Your information

Our <u>Privacy notice</u> explains what we do with the personal data you provide to us, and set out your rights. Our retention schedule can be found <u>here</u>.

Yours sincerely



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