Using the NHS number to share data

WHY AND HOW?

A number of local areas have been criticised in Ofsted and CQC inspections for lacking robust data on children and young people with SEND. Such a lack of data limits their ability to commission effectively or to monitor outcomes.

In response a number of local areas such as Middlesbrough (full case study can be found here) have responded to this by developing data sharing solutions. Such solutions rely on a 'unique identifier' so data on the same group of people can be extracted from different sources. In a number of local areas the NHS number is chosen for this purpose and is then appended to the Education Health and Care (EHC) Plan.

However, there has been some anxiety expressed by other areas seeking to do this about how they ensure that they stay within data protection legislation when using the NHS number in this way.
This briefing seeks to set out how to ensure that those wishing to follow this approach stay firmly within the law. It is adapted from legal advice provided by Steve Broach, Barrister, 39 Essex Chambers.

Background

Whilst the Children and Families Act 2014 and accompanying regulations do not specify that the NHS number should be included within the EHC Plan, they do not exclude it from the potential other information to be included in an EHC Plan where relevant. For example the child or young person's date of birth is also not specified information yet it is plainly necessary and appropriate to include the date of birth on an EHC Plan.

General Data Protection Regulation (GDPR) and the Data Protection Act 2018 ('DPA').

This scheme applies to 'personal data', which is defined in section 3(2) DPA as 'any information relating to an identified or identifiable living individual'. As such a child or young person's NHS number is plainly their 'personal data' for the purposes of the data protection scheme.

The scheme applies to 'processing' of personal data; there can be no doubt that including a child or young person's NHS number on their EHC Plan amounts to 'processing' of that data.

The local authority as 'data controller' is obliged to ensure that children and young people's NHS numbers are 'processed' in accordance with the GDPR principles which means that you must identify valid grounds under the GDPR (known as a 'lawful basis') for collecting and using personal data'.

Local authorities will therefore need to identify a lawful basis for obtaining a child or young person's NHS number, recording it on their EHC Plan and disseminating it with the Plan. The most obvious lawful basis here will be 'consent', described in the Information Commissioner's Office (ICO) guidance as applying where 'the individual has given clear consent for you to process their personal data for a specific purpose'.

The ICO guidance states that 'The GDPR sets a high standard for consent'.[1] Importantly, 'Consent means offering individuals real choice and control. Genuine consent should put individuals in charge, build trust and engagement, and enhance your reputation.' As such it is essential that local authorities do not apply any pressure on children, young people or parents, whether directly or indirectly, to agree to the inclusion of the NHS number on their EHC Plan. For example, it would be unlawful for a local authority to require consent to the inclusion of an NHS number in an EHC Plan before it finalises the Plan.

The ICO guidance sets out clear instructions on consent and can be found in Appendix 1.

The ICO's checklist on asking for consent includes a helpful and particularly relevant self-assessment questionnaire which local authorities may find it helpful to complete.

The more detailed supplementary guidance on consent issued by the ICO states that 'If you rely on consent, this will also affect individuals' rights. People will generally have stronger rights when processing is based on consent – for example, the right to erasure (also known as 'the right to be forgotten') and the right to data portability.'

It is vital to get consent right as the ICO guidance emphasises that 'Public authorities, employers and other organisations in a position of power may find it more difficult to show valid freely given consent'. Enforcement bodies are likely to apply particularly stringent scrutiny to their use of consent if there is a complaint or legal challenge.

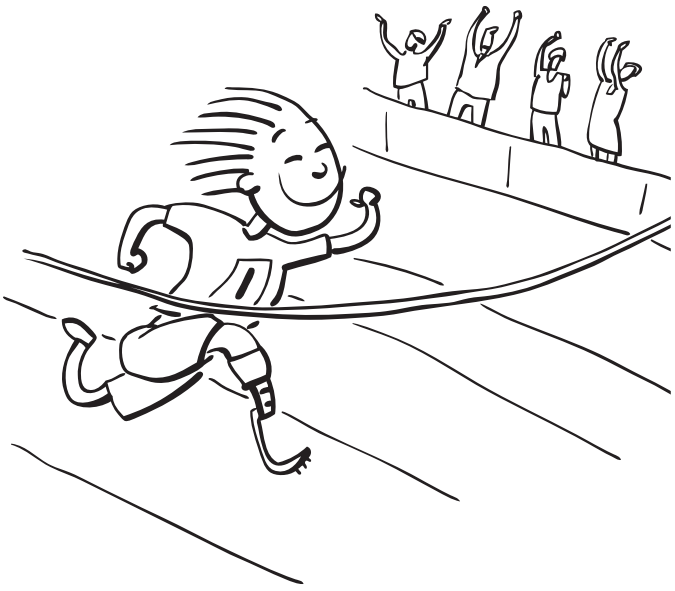
1. https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/

The complexities around consent as a lawful basis for data processing have led the ICO to produce discrete guidance in this area https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/consent.

Particular issues relating to consent

By children:

In relation to consent by children under 16, the ICO guidance states that 'the general rule in the UK is that you should consider whether the individual child has the competence to understand and consent for themselves (the 'Gillick competence test')'. As such children who are 'Gillick competent' in relation to the question of whether to give or refuse consent should be asked themselves; otherwise consent should be requested from their parents.



The ICO guidance on children and the GDPR includes as part of the self-assessment checklist 'When relying on consent, we make sure that the child understands what they are consenting to, and we do not exploit any imbalance of power in the relationship between us'. Of course given their impairments many children with SEN will not be competent[2] to give or refuse consent to the inclusion of their NHS number on an EHC Plan, and so consent will need to be obtained from their parents. Parents should be able to rely on their parental responsibility to give consent for any child or young person up to the age of 18, although the position in relation to 16 and 17 year olds is complex and specific advice may need to be sought for this group.

By those who lack capacity to make the relevant decision:

For young people aged 18 or over who lack capacity to make the relevant decision here, it may well be that this is a decision which can be made in their 'best interests' under the Mental Capacity Act 2005. However if there is concern in this regard then unless there is a health and welfare deputy or person with power of attorney then an application will need to be made to the Court of Protection. This would seem to be disproportionate in most cases, but local authorities will again need to seek case specific advice.

Generally:

There is a helpful checklist in the ICO's supplementary guidance of situations in which an organisation will *not* have valid consent to the processing of personal data.

2. Or will lack relevant capacity in the case of 16- and 17-year-olds; see the following paragraph.

Is a child or young person's NHS number 'special category data'

Special category data is data that is regarded as particularly sensitive and includes 'data concerning health'. This is defined as 'personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status'.

The ICO guidance on special category data states this definition 'not only covers specific details of medical conditions, tests or treatment, but includes any related data which reveals anything about the state of someone's health'. It is likely that a person's NHS number would fall within this definition. If a third party obtained a child or young person's NHS number, it could 'reveal' information about his or her health status. Although an EHC Plan will itself contain significant amounts of information about a child or young person's health, an NHS number could 'reveal' significant further information, for example an appointment for a test for a condition which is suspected but not yet diagnosed, or a health problem which does not impact in any way on the child or young person's education.

As such in our view local authorities will need to meet the additional requirements of processing special category data if they wish to include the child or young person's NHS number on their EHC Plan. This means they require 'explicit consent', see Appendix 1.

The ICO guidance states that 'if you process special category data you must keep records, including documenting the categories of data'; include information about categories of data in your privacy notice and other privacy information for individuals. If you are processing special category data, you should make this clear and specify which categories of data. You don't have to say which condition you are relying on, but you do need to state the lawful basis relied upon, as you would for any other personal data.'

Summary

It is possible for local authorities lawfully to include children and young people's NHS numbers on their EHC Plans, but only if 'explicit consent' has been obtained from the child, parent or young person (as applicable). This means that the usual 'consent' requirements set out above in relation to personal data are fulfilled, plus the additional three requirements to make consent 'explicit'.

Appendix 1 – ICO Guidance on consent

The ICO guidance on consent includes the following relevant instructions which local authorities seeking to rely on the consent lawful basis will need to keep well in mind:

a. Consent requires a positive opt-in. Don't use pre-ticked boxes or any other method of default consent.
b. Explicit consent requires a very clear and specific statement of consent.
c. Name any third party controllers who will rely on the consent.
d. Make it easy for people to withdraw consent and tell them how.
e. Keep evidence of consent – who, when, how, and what you told people.
f Keep consent under review, and refresh it if anything changes.

The ICO states that requests for consent should include:

a. the name of your organisation;
b. the name of any third party controllers who will rely on the consent;
c. why you want the data;
d. what you will do with it; and
e. that individuals can withdraw consent at any time.

Explicit consent:

The ICO guidance on special category data states 'Given the risks to individuals, there is more emphasis on explicit consent for special category data. However, this justification is not required for all conditions, and even where it is required the law acknowledges there may be good reasons why you can't get valid consent in some cases. If you're not sure which condition is appropriate, it can be useful to start by considering whether you could reasonably get explicit consent for your processing.

The ICO suggests that the additional requirements for consent to be 'explicit' are:

1. It must be confirmed in a clear statement (whether oral or written), rather than by any other type of affirmative action;
2. It must specify the nature of the special category data; and
3. It should be separate from any other consents you are seeking.

Appendix 2 – Gillick competence

See chapter 7 of *Disabled Children: A Legal Handbook* (Legal Action Group, 3rd ed, 2020) for detailed consideration of the principles of 'Gillick competency'. The tests for Gillick competency are similar for those in relation to capacity under the Mental Capacity Act 2005 for those aged 16 or over, involving being able to understand, retain and weigh up relevant information and communicate a decision.

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector with a membership of over 200 voluntary and community organisations and an active network of practitioners and policy-makers that spans education, health and social care. Their aim is to see a fully-inclusive society where disabled children and young people and those with special educational needs can lead full and happy childhoods and rewarding adult lives. They do this by working with the sector to find out what is and isn't working on the ground and use what they learn to influence policy and improve practice.

CDC hosts the following networks and projects:

Early Years SEND Partnership
IASS Network
Making Ourselves Heard
Special Educational Consortium
The Information, Advice and Support Programme
Transition Information Network

CDC is proud to be part of the National Children's Bureau (NCB), a leading children's charity working to build a better childhood for every child.

CDC is also part of the consortium that delivers the Every Disabled Child Matters campaign.