

January 16, 2017
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NHS England Child Health Transformation Team, england.healthychildren@nhs.net
cc Duncan Selbie, Public Health England
cc Garry Coleman, Head of Data Access, NHS Digital

I write to you with reference to plans outlined online¹ for the expansion of linkage of children's health data and any further linkage with education records in plans for child health.

In principle, personal data must be collected for specified, explicit and legitimate purposes and not further processed in a way incompatible with those purposes. Distinctions exist between direct and indirect care.

Please can you provide the following information in order to clarify some of the proposals and future plans:

- Privacy Impact Assessments made for these datasets and plans for their use and respective linkage
- What public communication is planned to all families of children whose data will be affected collected to date, and on a rolling basis for future collection or change of future scope for data already held
- What options are available to opt out of all or any of the planned datasets linkage - while the description says, "Young people and families can set their own preferences for information sharing and see who subscribes to their information." there is no description for those who do not wish to share any information with third parties or have it extracted and stored for secondary purposes in the first place.
- What limitations and safeguards are in place around "Knowing where every child is and how healthy they are" at all times? This is arguably a duty for parents and the individual and the overlap with duties of care for professionals should not encroach what is reasonable. A principle underlined by the Supreme Court on the sharing of sensitive personal data of children, in the Named Persons ruling² in , "within the rights protected by article 8 of the ECHR" (Para. 78).

The current consent model means individuals may choose to not have an SCR or share GP data with NHS Digital. This must be respected and improved upon, not undermined by new use of personalised children's records across a range of groups with a variety of purposes.

Parents do not consent to the PDS and associated tracking mechanisms and have a right to opt out of data flows to NHS Digital implemented in 2016. If this programme will "mandate electronic information flows from GP systems"³ are those same rights being respected and communicated to all children from birth, on registration with a GP and on a rolling basis?

The data within the Red Book and newborn screening in particular, as referenced on page 50 of the Healthy Children" Forward View⁴, is highly sensitive. Current policy and collection practice fails to ensure adequate consent⁵ or ensure communication for future change of purposes or expanding data users. There is little solution outlined in the report Better Births: Improving Outcomes of Maternity Services in England (3.29).

Data sharing beyond direct care purposes does not currently meet adequate fair processing for any secondary purposes. This has potentially catastrophic effects for child health should public trust fail, if it were found that these data were not used in ways the public expect, or that fail to ensure a social license for research.⁶

Thank you for your consideration. I am happy to answer any questions at any time.

Sincerely,

Jen Persson

Coordinator, defenddigitalme

¹ <https://www.england.nhs.uk/digitaltechnology/info-revolution/digital-primary-care/child-health/>

² <http://www.bbc.co.uk/news/uk-scotland-scotland-politics-36903513>

³ p75 <https://www.england.nhs.uk/wp-content/uploads/2016/11/healthy-children-transforming-child-health-info.pdf>

⁴ *ibid* p.50

⁵ http://defenddigitalme.com/wp-content/uploads/2016/09/DDM_Newborn_Screening_Consultation2509.pdf

⁶ Carter, P., Laurie, G., Dixon-Woods, M. (2015) The social licence for research: why care.data ran into trouble, *J Med Ethics* 2015;41:404-409 doi:10.1136/medethics-2014-102374