The Coroners and Justice Bill: Clause 152

The Coroners and Justice Bill was introduced into the House of Commons on 26th January 2009 and is currently at committee stage. The Committee has been asked to report by March 5th.

We are profoundly concerned by Clause 152 in Part 8 of the Bill which seeks to amend the Data Protection Act to remove barriers to the sharing of individuals' sensitive data without consent, and allow the sharing of information that was collected for one purpose to be used for an entirely different purpose.

A Secretary of State would be empowered to make an 'Information Sharing Order' in pursuit of any 'policy objective', to be approved by affirmative resolution, which would give 'any person' the right to share information. This power is not restricted to sharing between government departments: it would also allow private companies to share personal data if an order were made to allow it.

The Explanatory Notes to the Bill say that the intention is to create:

'… a free-standing power for ministers to enact secondary legislation which will have the effect of removing all barriers to data-sharing between two or more persons, where the sharing concerns at least in part the sharing of personal data, where such sharing is necessary to achieve a policy objective…' [1]

As Liberty's briefing[2] explains, an Information Sharing Order:

'…can confer power on any person; remove or modify any legal prohibition on information sharing and amend or repeal any Act of Parliament whenever passed. The examples given in the Explanatory Notes state: "This could be by repealing or amending other primary legislation, changing any other rule of law (for example, the application of the common law of confidentiality to defined circumstances), or creating a new power to share information where that power is currently absent." ' [3]

NO2ID and Privacy International have compiled a list of examples from the almost limitless information sharing opportunities that Clause 152 would permit both within government and between government and commercial organisations. The full list can be found on pages 4 to 6 of PI's 'Black Zone' report, 'SHARING THE MISERY: the UK's strategy to circumvent data privacy protections',[4] but it includes:

- Provision without patient consent of NHS files to medical research organisations;
- Massive expansion of the national DNA database, including for purposes other than the detection of crime;
- Bulk provision of NHS and other medical files to the insurance industry;
- Full disclosure of telecommunications data from service providers to government;

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[1] Para 962 Explanatory Notes

[2] Second Reading Briefing, Liberty: http://www.liberty-human-rights.org.uk/pdfs/policy-09/coroners-and-justice-second-reading-briefing.pdf

[3] Para 697 Explanatory Notes

[4] http://www.privacyinternational.org/countries/uk/uk_data_sharing_report.pdf

- Automatic population of the National Identity Register with, e.g. complete electoral roll and tax records (effectively, near-universal registration without consent)

The British Medical Association has expressed serious concern about Clause 152 in a briefing note to MPs:

'It appears to permit an unprecedented sharing of confidential personal health data… This Bill strips patients and doctors of any rights in relation to the control of sensitive health information. In the BMA's view it will also fall foul of Article 8 of the Human Rights Act.'

Genewatch is particularly concerned about what the proposals mean for DNA and genetic information[5]:

'Blood samples are often collected in the NHS to do medical tests, including from every baby at birth. The information-sharing powers mean that these samples could be analysed by private companies to obtain genetic information without your knowledge or consent. This information could then be shared with others, also without your knowledge or consent. A national DNA database could be built by stealth in the NHS, with access later given to the police.'

The Government has already advanced the possibility of collecting babies' DNA at birth in a white paper published in 2003.[6] Although the Human Genetics Commission advised against this in 2005,[7] pointing out the impossibility of obtaining a child's consent for an action that holds lifelong implications, the Government's position is due for review in 2010. Recently the Minister of State for Public Health, The Rt Hon Dawn Primarolo MP, and Professor Dame Sally Davies, Chief Scientific Adviser to the Department of Health, made clear the Government's long-term objective of creating linked genomic and NHS records.[8]

ARCH is concerned that large quantities of sensitive information are now collected about children, and obtaining consent before this is shared with others is crucial to the effective maintenance of children's right to confidentiality. This is important to the dignity of each child, and also to ensure that they access the services that they and their families need.

We have seen five separate research studies in recent years concerned with children's views on information-sharing. All have emphasised children's concerns about confidentiality, and some have indicated that children would be unwilling to use services if they were not confident that their confidentiality would be respected. No practitioner could offer meaningful assurances that sensitive information would be kept private when the possibility existed that a subsequent Information Sharing Order could obviate a child's request for confidentiality.

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[5] http://www.genewatch.org/sub-563487

[6] 'Our Inheritance, Our Future: realising the potential of genetics in the NHS', Department of Health, 2003. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006538

[7] 'Profiling the Newborn', Human Genetics Commission 2005 http://www.hgc.gov.uk/UploadDocs/Contents/Documents/Final%20Draft%20of%20Profiling%20Newborn%20Report%2003%2005.pdf

[8] Q888-892 Uncorrected evidence to House of Lords Science and Technology Committee, 21st Jan 2009 http://www.publications.parliament.uk/pa/ld/lduncorr/scii210109ev15.pdf

The idea of using secondary legislation to allow information to be shared was put forward in the *'Data Sharing Review'*[9] carried out for the Ministry of Justice by Dr Mark Walport, Chief Executive of the Wellcome Trust, and Richard Thomas, the Information Commissioner, acting in an independent capacity. But the recommendations never suggested such enormously broad 'Henry VIII' powers that would allow, by Order, the arbitrary amendment of any piece of primary legislation.

In his capacity as Information Commissioner, Richard Thomas has since pointed out that Clause 152 of the Bill goes far beyond the recommendations made in the Data Sharing Review Information Sharing Orders:

'The Bill's information sharing provisions would be significantly improved if they mirrored more closely the relevant recommendation of the Thomas / Walport Data Sharing Review. The recommendation was to provide a statutory fast-track procedure for use in circumstances where there is a genuine case for removing or modifying an existing legal barrier to information sharing. The recommendation made it clear that the procedure should only be available in precisely defined circumstances.'[10]

JUSTICE similarly points out in its briefing for second reading in the Commons:

'We note that the recommendation of provision for data-sharing orders of the Data Sharing Review was far more limited and cautious than the proposals contained in Part 8. In particular, the Review noted the 'exceptional and potentially controversial nature' of such orders, and emphasised the need for 'necessary conditions and safeguards'. In our view, the grossly general provisions of Part 8 in no way constitute an adequate set of safeguards against the potential for disproportionate interference with Article 8 that data-sharing orders are likely to involve.'

Finally, we are alarmed that such a sweeping power is contained in the final clauses of a lengthy Bill that deals with issues unrelated to data protection. The justification for doing so has been advanced as relieving bereaved families of the need to notify several different agencies following a death. In fact this situation could be dealt with simply by seeking consent to share information when a death is registered. Because the Committee has to report by March 5th, the amount of time available for Committee scrutiny is very limited and clause 152 is unlikely to get the attention that it needs.

Several organisations have signed a letter to the Secretary of State for Justice, raising the many concerns about Clause 152 and requesting its deletion from the Bill. A copy of the letter is attached with this briefing. If your organisation would be willing to support this letter, please could you contact NO2ID, and we will ensure that your signature is added to it.

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February 26th 2009

(With thanks to Terri Dowty of ARCH, for providing the framework briefing)

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[9] The Data Sharing Review can be downloaded from: http://www.justice.gov.uk/reviews/datasharing-intro.htm

[10] Memorandum submitted by the Information Commissioner (CJ 02) to Public Bill Committee Jan 2009 http://www.publications.parliament.uk/pa/cm200809/cmpublic/coroners/memos/ucm202.htm