

Children's Rights Alliance for England

Data Sharing Review

13 February 2008

Response from the Children's Rights Alliance for England¹

Introduction

In light of recent legislative developments resulting in the retention of extensive personal data on every child and young person living in England (through the ContactPoint database) and the expansion of electronic information sharing (through the e-CAF system) on children and young people in receipt of services, this response focuses on the privacy and access rights of, and consent issues relating to, children and young people.

The Children's Rights Alliance for England (CRAE) has particular concerns about the ContactPoint database, especially when considering a child's right to privacy under the European Convention on Human Rights² and the UN Convention on the Rights of the Child (UNCRC). Article 16 of the UNCRC states that: *'no child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour or reputation. The child has the right to the protection of the law against such interference or attacks'*.

This paper will also touch upon broader issues particular to children and young people that must be comprehensively addressed by the Data Sharing Review in relation to consent, data retention, data security, child protection, and the provision of adequate support to enable children and young people to influence decisions made about their personal data.

Protecting the right to privacy

Research for the Information Commissioner carried out by the Foundation for Information Policy Research found that the data sharing arrangements it investigated (which included the information sharing index [now ContactPoint] and the CAF) *'threaten and may violate in particular the provisions in the (UN)CRC emphasising the need for*

¹ The Children's Rights Alliance for England (CRAE) is a coalition of over 380 voluntary and statutory organisations committed to the full implementation of the United Nations Convention on the Rights of the Child. This briefing has been prepared by the Secretariat of CRAE and is not necessarily supported by our member organisations.

² Article 8 of the European Convention on Human Rights lays down the right to respect for private and family life.

respect of the family as a group (Article 5) and the need to respect the right of a child to a private life (Article 16)’³

ContactPoint

CRAE believes the Government has not given sufficient consideration nor taken sufficient action to protect children’s privacy rights. Introducing a national database containing information on every child in England (ContactPoint) has prompted serious concerns as to whether such data retention is proportionate. We feel it important to reiterate the concerns of the Joint Committee on Human Rights in 2004 in relation to the ContactPoint database, namely that *‘if the justification for information sharing about children is that it is always proportionate where the purpose is to identify children who need child welfare services, there is no meaningful content left to a child’s Article 8 right to privacy and confidentiality in their personal information’*.

This is supported by the third principle of the Data Protection Act 1998, that personal data must be *‘adequate, relevant and not excessive’* in relation to the purposes of collecting that data.

Parliamentarians, the Information Commissioner, child protection experts and information security specialists alike have expressed serious reservations about the extent of the proposed information sharing, the likelihood of security breaches, and the risk that children at risk of significant harm will be overlooked in a plethora of low-level data on all children. While we welcome the independent assessment of ContactPoint’s security measures that has recently taken place, we continue to question whether it is necessary, or justifiable given the vulnerability of children and young people, to track every child in England in this way. We maintain that the ContactPoint database poses an unacceptable risk to the integrity of children’s personal data, and an immense threat to their right to privacy.

Further questions urgently need to be answered about ContactPoint:

- Is it genuinely proportionate to the risks children face?
- Are we in danger of influencing perceptions of individual children and young people by retaining unnecessary information about them?
- How can we combat misinformation that may discourage children and young people with privacy concerns from accessing much needed services?
- On what criteria do practitioners judge whether information on ‘sensitive services’ should be shared?

Common Assessment Framework

We have similar concerns about the Common Assessment Framework (CAF), which requires complex, far-reaching decisions to be made by often non-expert practitioners about a child’s welfare, capacity, and need for services. A number of the judgements required in the CAF are extremely subjective (e.g. on the state of familial relationships), and it is a serious concern that these judgements, once recorded, can be shared on an ongoing basis and as such have a substantial impact on the life of a child or young person. The e-CAF system also seems to have avoided the level of Parliamentary scrutiny undergone by the ContactPoint database – a concern given the in-depth nature of the information it contains. CRAE does not oppose the sharing of information about a child or young person, where it is clearly in his or her best interests (particularly where

³ Children’s databases – safety and privacy: a report for the Information Commissioner, page 121. Foundation for Information Policy Research, 2006

he or she is deemed to be at risk of significant harm) and where guidelines and safeguards on information sharing are fully applied. The danger arises when, as now, such information sharing becomes a matter of routine, and there is inadequate monitoring of compliance with data protection and human rights principles.

Confidentiality: Children and young people's views on information sharing

Children and young people themselves have very clear concerns about the ways in which personal information about them is used. One of the key messages emerging from a consultation run by CRAE in 2004 (commissioned by DfES) with children and young people on information sharing was that they wanted specific information from practitioners about why information would be shared, and with whom.

The overarching message from children and young people was that confidentiality was extremely important to them, particularly with regard to certain services. One child even commented, *'keep things to yourself if you don't want them to be shared...because the child might not want the things to be shared that's been happening'* (10 year old). Clearly this is a problem. On a more positive note, the children consulted were open to the idea of information sharing, provided that practitioners *'talk it through and say exactly who they are going to pass it on to, and why they're doing that, and what the reasons are for that...and you should have permission, a signature so that you know that you've given your consent to do that'* (16 year old).

Research by the Children's Rights Director (published in January 2007) supports CRAE's findings that children feel very strongly about their right to privacy. While the children questioned did not object to certain adults having access to their personal information, they were less tolerant of others accessing information about them. Comments included, *'They will know too much about me'*, and *'it's not their business'*. Children and young people said there had to be strict rules about who could access their information, and that these people needed excellent training before using the database. They also thought all children should be able to check if the information held about them was correct, and that all information should be removed once a child reached the age of 18.

The expansion in data being stored on individual children and young people, and the number of practitioners who will have immediate access to this, will make it difficult (perhaps impossible) to know where information about a particular child or young person will end up, despite existing information sharing and data protection guidelines. If this is the case, how can informed consent by children to the sharing of information really be given?

Consent

Consent from children and young people to the sharing of information is often seen as a matter of good practice rather than a requirement, made clear in guidance documents originating from the Government. Seeking consent should be mandatory; recommendations made by the Data Sharing Review should emphasise the necessity of a child or young person giving, or being able to withhold, **free, informed and explicit consent**. It should be made clear that such consent should only ever be sought in situations where children feel able to give or withhold consent freely, with no pressure to comply exerted (whether intentionally or not, by virtue of say, a school environment, or an implied loss of access to services) by parents, practitioners, teachers or other professionals.

One-off consent, even if written or explicit, should not be deemed sufficient for data to be retained and shared on an ongoing basis. Government guidance states that consent should be regularly reviewed; we would argue it should be reviewed for every incidence of significant information sharing, particularly where the nature of the information is sensitive. Existing guidelines also allow for subjective decisions to be made about when a child's consent, or lack thereof, can be overridden. Consent from a child or young person should never be easily put aside, particularly given the value placed on confidentiality by children and young people when deciding to access certain services.

There is a danger that the identification of universal, targeted and sensitive service practitioners on the ContactPoint database will lead to practitioners making assumptions about a child, and sharing information more readily than would have previously been the case, with less consideration for the need for such an action. It must be continually emphasised that practitioners are *not* obliged to share information about a child simply because their involvement with a particular service has been recorded on a database. Existing guidelines on sharing information – ensuring consent, informing the young person where the information will be going, determining whether the information should indeed be shared – must *always* be reiterated and applied.

The Spine database will soon contain the health care records for all patients in England. The Care Record Guarantee, published in 2007, states that parents are allowed to see their child's record on request, and that a child may be asked for his or her agreement if he or she is '*able to understand and make decisions*'. If a child has this capacity, he or she is also entitled to see his or her records. While it is possible for an individual to opt out of the system by writing to his or her local GP, it is unclear whether children and young people are accorded the same opt-out rights as adults. This is another example of unclear consent procedures for children and young people.

Underlying this whole area is the question of at what age a child or young person can be deemed competent to give informed consent, who makes that judgement, and how parents should be involved in issues of consent. The Foundation for Information Policy Research carried out detailed research for the Information Commissioner on the safety and privacy implications of children's databases in 2006, and found that local practice and interpretation around consent and competency differed widely, and that ethical practice was often contingent on knowledge of case law to understand the wider implications of consent.⁴

Transparency and access rights

It is important that children and young people understand what data is held about them and what it may be used for, and that subject access request procedures are accessible for those of all ages. At present, local authorities are required (in the draft ContactPoint guidance) to 'suitably' publicise the address for requesting information – this could be interpreted in any number of ways in practice. Local authorities should be specifically required to make information about data collection and retention easily and proactively available to children and young people in a format they can understand; this must also be the case when responding to subject access requests from children and young people. This information must be consistent from authority to authority, and between partner organisations, especially in relation to highly mobile children whose records may

⁴ Children's databases – safety and privacy: a report for the Information Commissioner. Foundation for Information Policy Research, 2006

be held by more than one authority over the course of their childhood, to ensure children are not discouraged from accessing services by fear their privacy will be compromised.

When determining whether children and young people have sufficient understanding to exercise their access rights, local authorities and other bodies must be required, for children and young people, to use the same indicators for determining levels of understanding as are used in juvenile justice and social care cases, with reference to the UNCRC and relevant domestic legislation. Such an important right to access information held about oneself must not be reduced to a subjective decision by an individual, simply because the request comes from a child or young person.

To deal with all these points, there is a need for appropriate and ongoing training for practitioners on how data protection and information sharing provisions apply specifically to children and young people.

Children and young people must also be supported to take action where they feel there has been a breach of their privacy, or where the need for informed consent when sharing information has been unduly disregarded. This needs to be addressed by the introduction of child-friendly complaints mechanisms which are well-publicised and accessible.

Summary of key concerns

CRAE asks that the Data Sharing Review consider in detail the following issues in relation to children and young people:

- The erosion of children's privacy rights through automated data sharing – taken together, the number of individual databases containing data on children and young people (for example ContactPoint, e-CAF, Spine, the Integrated Children's System) gives legitimate access to children's personal information to an unprecedented number of individuals.
- Is ContactPoint proportionate? Is it really necessary to retain the details of every child and young person aged 17 and under in England? The rationale for the ContactPoint database in particular must be urgently reconsidered in light of the significant security, privacy, transparency, accuracy and proportionality concerns raised by experts in the field, and not least in relation to the concerns of children and young people themselves about what information is held about them, and where it goes. This is particularly urgent given the recent leak that the Home Office will target young people in its initial roll out of ID cards.
- The validity of consent – guidance from the Information Commissioner is urgently needed given the massive increase in data held, and the related consent issues raised in this paper.
- The difficulty faced by practitioners in supporting children, young people and parents to give informed consent to information sharing, when they themselves are not specialists in information sharing, privacy rights and data protection, and the need to address this through explicit guidance and good training.
- Establishing a clear independent lead for the protection of children's privacy rights, particularly but not exclusively in relation to computerised databases. This could be done through extending the statutory duties of the Information Commissioner to

include monitoring the operation of the ContactPoint database with a particular focus on the protection of children's privacy rights, and safeguarding the role of parents in advising children on the enjoyment of their rights. This lead should also ensure that local authorities recognise sharing information about children and young people as a serious decision requiring significant oversight. Complaints procedures should be introduced which are child-friendly, well-publicised and accessible.

- Guidance for practitioners needs to be more explicit about the importance of the privacy rights laid out in international and domestic law (the European Convention on Human Rights, the Human Rights Act 1998 and the UN Convention on the Rights of the Child) – at present, there is no mention of any of these in the practitioners' guidance to the CAF, and only a brief reference to the Data Protection Act in the managers' guide to the CAF.

Contact details