Response to: James Dornan, Convener – Education and Skills Committee

Subject: NHS Lothian Response to Consultation on the draft Code of Practice, the Children and Young People (Information Sharing) (Scotland) Bill.

1.0 NHS Lothian welcomes the opportunity to comment on the Children and Young People (Information Sharing) (Scotland) Bill to the Education and Skills Committee.

1.1 Overall, the Code of Practice on information sharing is welcomed by NHS Lothian.

2.0 The purposes of information sharing have not been defined and remain unclear in the code of practice. This had led some people to consider this term vague and to worry about the limits to information sharing. It should be possible to set out the context:

2.1 Current arrangements Some information sharing about all children is necessary to ensure that their health is protected in schools. The existing requirement for, e.g. health and education to share information in order to provide basic services, needs to be acknowledged and as set out explicitly in the code of practice. This includes sharing basic information necessary to provide health services such as immunisation, vision screening, dental inspection etc as set out in NHS Acts etc. This could be referenced explicitly. The current wording has the potential to weaken existing mechanisms designed to protect children.

2.2 Children with health problems A proportion of children will have chronic health problems and services working with each child need to know enough to help them stay well and to respond appropriately to exacerbations or urgent situations. This is a Team around the child approach. In most situations a general consent is given when using services and the limits to confidentiality explained. It will not always be possible to gain consent and in such cases independent advocacy should be available and multiagency case conferences undertaken where required.
2.3 **Risks to children’s health that need multiagency input to be addressed effectively** A proportion of children in Scotland currently face very real threats to their physical and mental health, educational development and ability to grow up to be successful adults. Up to 30% of children are growing up in poverty, at least 15% children not meeting developmental milestones at 27-30 months, 17% developmentally vulnerable at school entry


Denholm R et al. Child Abuse Review 2013; 22:30-33 DOI: 10.1002/car.2235). Addressing these issues successfully for affected individuals is complex and requires multiagency involvement and information sharing so that they can apply their expertise. Clearly, and thankfully, with effective multiagency intervention most of these children will never meet the threshold for child protection but reducing avoidable harm through information sharing must be seen as part of our duty to one another as residents of Scotland.

2.4 **How we protect confidential information in Scotland – addressing unwarranted variation.** The existing arrangements for protecting confidential health information in Scotland are recognised as good practice. This is not highlighted in the code of practice. Every health board has a Caldicott Guardian who is a senior health professional. It would be really helpful if, as part of the Code of Practice all organisations were required to have a professional with a similar role – this would complement the requirement for organisations to have a Data Protection Officer under the General Data Protection Regulation.

2.5 **Taking account of what the public has already told us** Scottish Government has consulted widely on the use and application of personal health data for research etc. (e.g. http://www.scotship.ac.uk/c4.html; Aitken M et al https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-016-0153-x) , https://doi.org/10.1093/scipol/scv075). This, and related work should be used to inform the code of practice and be part of the programme of engagement for professionals and public.

3.0 **Content**

3.1 **Plea for an easy read document** The content is hard to understand. It appears to have been written by lawyers for application by Caldicott Guardians and Data Protection professionals. The 7th Caldicott principle was introduced because professionals were reluctant to share information necessary to provide safe, effective care and protect children and adults. It is essential, therefore, that the Bill and supporting documents is translated bill into an easy to understand
format and language. The minimum should be Plain English and Easy read.

**3.2 Public engagement** Before publication of the final version workshops with children and young people and the wider public about the Bill and code of practice etc should be held. These would be designed to ensure a common understanding of the issues that the Bill is addressing, the procedures in place to protect confidentiality and the primacy of children’s needs.

**3.3 Oversimplification of when informed, explicit consent is required**
The code states consent should be sought from individuals prior to sharing information unless sharing without consent is required in order to protect the “vital interests” of the child. A clear definition of “vital interests”, backed by Central Legal Office advice and the mechanisms for ensuring that the interests of the child are paramount is required.

**3.4 Clarity regarding the position of 12 and 13 year olds giving their own consent**
When teenagers give their own consent e.g. to immunisation there is some evidence that uptake increases. Usually this is not because parental support has been withheld but reflects loss from school bag, wording on national forms, forms being mislaid etc. Children’s rights in law may be challenged by parents so it is important that the position is clear.

4.0 Training

**4.1 Guidance for professionals** To further support agencies as part of GIRFEC implementation and build staff confidence with information sharing and consent issues the addition of practitioner guidance would be beneficial. It could provide clarification and detail at a practice level around information sharing, consideration as to the level of sensitivity, informed consent etc.

**4.2 Practical guidance and training for practitioners** Training will be requested by professional bodies, staff and unions. National Practitioner guidance could provide the core of these training packages.

**4.3 Communication and awareness raising for all professionals, staff and trades unions** This would help reduce the risk of inconsistency of message and/or practice.

**4.4 Be clear that consent is only one approach** Support professionals to take each case on its own merits and provide training on when
alternatives to consent are appropriate.

4.5 **Recognise complexity with worked examples that illustrate good practice** Any guidance should include practice examples and scenarios which could be used to develop training materials to be used across Scotland to help minimise the risk of inconsistencies arising in different parts of the country in relation to interpretation and/or practice. Discordance in consent and inconsistency of decision making between estranged parents, for example, is not uncommon.

4.6 **Collect examples of dilemmas that professionals, families and organisations face, work through them collaboratively and publish the guidance that results as updates to the Code of Practice**

4.6.1 For example, in working to prepare a child for discharge from hospital and negotiating a package of care, NHS will be working closely with the parents and the family. The family will have granted permission for NHS staff to discuss with LA staff prior to discussion. The view from some NHS Lothian staff is that if in discussion with a local authority colleague it becomes apparent that they don’t know something specific relevant to the discharge, then the NHS staff member would tell the social worker. The question is – have they gained consent or not. This is where we need to demonstrate some pragmatism about the consent and that it all relates to the same situation/discharge/package, etc.

4.6.2 The legal requirement where a family refused to accept the offer of the Named Person and how we manage related information where the offer of the service is refused

4.6.3 Given the definition of when a plan is required – promote support OR safeguard a child – in health visiting that could be all children – further definition of this is required

5.0 More information required on how staff manage information when the family have refused consent to share where this information would promote or support the child or family (e.g., when a child has an S&L need and the parents refuse consent to share this with the independent school) Is there anything we need to consider about the rights of the child or should the Code define that the rights of the parents over rule this.

5.1 **Provide examples of consent being unreasonably withheld** The Code raises the concept of people unreasonably withholding their consent but does not specify in what ways a refusal to give consent may be seen as unreasonable. This is an example of an issue which could be further explained in practitioner guidance.

6.0 Common messages
6.1 **Standard script and Q&A** For communication and awareness purposes national messages would support communication managers with a standardised script.

6.2 **Set out how the code of practice aligns with existing professional obligations**

While professionals will have their own ‘code of practice’/guidelines aligned to their profession, national practitioner guidance would assist in providing a shared common language. The existing wording in the code of practice should be refined to reflect how it would be used in practice. It should link explicitly to other codes of Practice and advice e.g. NMC /GMC/ BMA etc and make it very clear where the codes are aligned as well as the reasons for any differences. Whilst additional guidance is expected, the Code itself should be clear and concise as practitioners will be using this for decision making at the point of care.

**Giving Oral Evidence to the Committee**

NHS Lothian wishes to give oral evidence.

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