GMC response to the Scottish Parliament’s Education and Skills Committee call for evidence on the Children and Young People (Information Sharing) (Scotland) Bill

Comments on the Bill

We warmly welcome the proposed move away from creating a mandatory duty to share information about children and young people with a Named Person.

Our main concern was that a mandatory duty could lead to routine sharing of information that is not relevant, necessary or proportionate in terms of facilitating action in support of a child or young person’s wellbeing. If routine sharing of this kind became prevalent, it would undermine children and young people’s trust in the basic confidentiality of health services. As a matter of general principle, we think it is important that doctors are able to use their professional judgement to determine what information about a child or young person it would be relevant and proportionate to share with third parties given the objectives being pursued.

We were also concerned that, given that most of the issues disclosed to a doctor by a child and/or their parent will have a relationship to the child’s wellbeing, it was likely to be a challenge for professionals in determining what information about a child should trigger the mandatory duty to share (given its broad terms).

We therefore have a strong preference for information sharing to be based on a consent model rather than a mandatory duty. This would be consistent with the duties we place on doctors in relation to disclosures involving concerns about child abuse, child neglect and child welfare.

The draft statutory code of practice

As we understand it, all persons who are considering whether to disclose information, or who are disclosing information, under Parts 4 and 5 of the Act, must do so in accordance with the statutory code of practice. This will include a range of professionals, including doctors.
In our view, the illustrative code of practice is not currently written with such a readership in mind. It sets out the relevant safeguards and law in quite legalistic terms, and does not help the reader to translate the legal requirements into the steps that should be taken in everyday practice.

As an example, paragraph 6 says that a service provider or relevant authority must tell the child or young person (or parent) if it acquires personal information that may be shared with another service provider. But no examples are given of when this might occur, or why the information would be shared without consent. This section might be readily understandable to a lawyer or information governance specialist working for a service provider or relevant authority, but its meaning is unlikely to be immediately clear to a healthcare professional who is not very familiar with data protection law.

Another example is paragraph 7, where the draft code repeats the wording of Schedule 2 of the Data Protection Act 1998, but does not expand on it. It is likely to be helpful to the non-specialist to have some examples of the sorts of legal obligations that would require data to be processed, and what is ‘sensitive personal information’ for data protection law purposes, and what is meant by ‘protecting the vital interests of the person to whom the information relates’.

More generally, it would be helpful if the code started with an overview of the relevant law that is to be covered in the code and a statement about how the different pieces of law interact. We have tried to give this kind of overview in straightforward language in the legal annex of our confidentiality guidance for doctors, which can be found on our website at www.gmc-uk.org/guidance/ethical_guidance/confidentiality.

In particular, it would be helpful to make clear at the outset that a disclosure would be unlawful under data protection law if it breached the common law duty of confidentiality. As drafted, the reader needs to get to paragraph 29 before the common law is mentioned and this could be misleading. For example, in paragraph 7 the impression is given that a disclosure without consent would be lawful if it is ‘necessary to comply with one of your legal obligations… or for the exercise of a function conferred on the person to whom the disclosure is made by legislation’. But these conditions may not be sufficient to satisfy the requirements of the common law.

It might also be helpful to sequence the guidance according to the order in which questions need to be considered – perhaps with a supporting flowchart – to support practitioners in their decision making. You can see how we have approached this through a flowchart at page 20 of our confidentiality guidance.

We appreciate it is not a straightforward matter to translate complex law into everyday language but we think it is vital that the code of practice is written in such a way that non-specialists can follow it. We understand that there will be a consultation on the code once the Bill receives Royal Assent, and we would strongly encourage direct engagement with healthcare professionals to make sure the code meets their needs, if that is not already planned.
Other guidance

We are not sure whether it would be a matter for the statutory code or for other guidance but we think it is important that there is clear guidance for healthcare professionals on the circumstances in which sharing information with the Named Person service is likely to promote, support or safeguard the wellbeing of a child or young person.

The statutory functions of the Named Person are currently described in very broad terms – they will advise, inform or support children/parents; help them access services; and advocate for them with service providers. Healthcare professionals will need a good understanding of what services the Named Person offers, what the benefits to the child, young person or parent would be, and how confidential information will be protected from further disclosure to facilitate a well-informed discussion with the child and their parent which helps them to decide whether to agree to information being shared with the Named Person. Healthcare professionals will also need this understanding to form a good judgement about what information will be relevant and proportionate to share.

In addition, if health professionals understand the practical ways in which the Named Person can act on behalf or in support of a child and their parent, they can become advocates for the Named Person role and help build trust in the service amongst children and their families. Doctors have the opportunity to mention the availability of the service more than once over a period of time, if they think it would be beneficial to the child or young person, knowing what the service can and can’t deliver may help them to feel confident about not pursuing the issue further with a parent who is clear that they do not wish to engage.

It will also be essential that children, young people and their parents have good clear information about their rights not to engage with the service, in accessible formats and language that they can understand. It will be important to consider how professionals are expected to capture families’ wishes so that they are not repeatedly asked about the issue which may put them under pressure to accept Named Person involvement.

More generally, we think guidance should support good practice in seeking consent as the usual basis for sharing information with the Named Person. Our guidance 0-18 years: guidance for all doctors outlines the key principles:

- Doctors should ask for the child or young person’s consent to share the information (paragraph 45).
- Doctors should inform the patient about the child or young person about the possible uses of their information (paragraph 43b)
- Doctors should explain to the child or young person why they are considering sharing information, and should take into account the views
given by the child or young person about whether and how their information should be disclosed (paragraph 49)

We also recognise that there may be cases where seeking consent may not be appropriate because it would increase the risk to the child, young person or their parent. In our 0-18 years and child protection guidance, we set out some circumstances in which information can be shared without consent. For example our child protection guidance states:

36. You can share confidential information without consent if it is required by law, or directed by a court, or if the benefits to a child or young person that will arise from sharing the information outweigh both the public and the individual’s interest in keeping the information confidential. You must weigh the harm that is likely to arise from not sharing the information against the possible harm, both to the person and to the overall trust between doctors and patients of all ages, arising from releasing that information.

We make clear that if a doctor shares information without seeking consent, or in the face of a competent refusal, the doctor should explain why they have done so to the people the information relates to, and explain:

- What information has been shared
- Who was provided with the information
- How the information will be used
- Where they can go for independent advice and support.

We would like to see the statutory guidance take a similar position on the circumstances in which consent should not be sought, and the information that should be provided to children, young people and their families when information is disclosed without consent.

Next steps
We commend the careful work of officials in the Scottish Government to date in engaging with a wide range of stakeholders to develop a Bill that is in line with the law and existing professional standards. We look forward to continuing to work with the Scottish Government to create policy and guidance that helps professionals to ensure that the rights of children, young people and parents are respected.