General
Medical
Council

GMC response to Welsh government consultation on Children missing education data

We have previously outlined our role as the regulator of doctors in the UK (and in the future physician’s and anaesthesia associate’s). We want to reiterate our support for Welsh Government’s aim of ensuring no children and young people are missing out on receiving a suitable education. We recognise the important role an appropriate education can play in maintaining and promoting the welfare of children and young people. Alongside these considerations it's important to recognise the central role that respect for patient confidentiality plays in building and maintaining a patient's trust in healthcare professionals and healthcare services.

Sharing relevant information about a child or young person with the right people, in appropriate circumstances, can help to protect children and young people from harm and ensure they get the support they need to improve their wellbeing. As we have previously set out, our professional standards for doctors provide an agreed framework for appropriate information sharing to support children and young people, balanced with their rights to confidentiality. We see this approach as crucial to upholding trust in the doctor-patient relationship. (Details are in Confidentiality: good practice in handling patient information and in Protecting children and young people: guidance for all doctors.)

We understand that as a result of consultation, Welsh Government has altered the proposed approach to establishing and maintaining the database. Instead of maintaining a list of all school-aged children, it will focus on those children and young people who may be missing in education. Although the database will eventually contain only this subset of children, the process of establishing it (as set out under the draft Regulations) still requires local health boards (and potentially GP practices) to share information about all children ordinarily resident within the local health board. The consultation indicates the amount of information to be collected about individual children is reduced to their name, address, gender and date of birth (without specific details of their parents or guardians). Although this requires disclosure of less confidential healthcare information, there are still a number of concerns about the proposal. In addition, the schedule in the draft Regulations continues to make reference to the name, address and postcode, telephone number and email address of all parents of the child, the name and address of the person providing their education, and any additional learning needs they have. As this information isn’t going to be requested, it’s important that these references are removed from the Schedule to ensure this information isn’t inadvertently shared.

Clarity about the basis on which information will be transferred between services

The draft Regulations state that Local Health Boards and general medical services contractors in Wales will be required to disclose information they hold about children and young people to their local authority. Sharing confidential information about a child with a third party, for a purpose not related to that child's health or welfare or justifiable as being in that child's best interests, should only happen where there is a clear legal basis for sharing. It is not clear if the regulations would create a legal duty on GPs (as GMS contractors) to transfer the required data to the LHB or LA (for the purpose of creating the database), that clearly overrides their data protection obligations and the common law duty of confidentiality that healthcare professionals owe to the patients they serve. If it is not clearly the case that the regulations would override these obligations, then there is a potential conflict with our professional standards which is likely to act as a barrier to the data being shared.

We note that LHB's would be transferring information that they already hold to the local authority. However, if this information is held as a result of being shared/extracted from primary care or secondary care systems, (for example automatic sharing when a patient registers with a GP surgery or attends for hospital care), then as we understand it, the patient (or their parent) would need to know beforehand (as part of data protection requirements) that details of the child's name, address and date of birth would be shared with the LHB/LA for the purpose of creating and maintaining the database, and may want to know the legal basis under which this information is being shared. If this is the case, as we flagged in our previous response, doctors (and other healthcare staff) would need to have clear, accessible information available to support conversations with children and their parents about what information is being shared and why, and who they can contact if they have concerns.

Justification for collecting data on all children

We continue to be concerned about the proposal, given that it seems to require doctors to share information with the LHB about all children and young people of school age who access their services, even though they are not the intended beneficiaries of the database.

The scale of information sharing proposed under the draft Regulations in order to identify a small subset who may be missing in education, seems disproportionate, without more details about why less intrusive approaches would not achieve the intended policy goals. Given our concerns about the potential conflict with our professional standards, we think it will be important to provide both doctors and patients with clear information about the rationale for collecting this data from confidential healthcare services, and the legal basis underpinning information sharing.

The impact on patient confidentiality and trust in healthcare services

We believe that, if health boards are required to share personal information about children and young people that they legitimately hold, for purposes not related to the child's health and welfare, doing so risks undermining public trust in the confidentiality of health services.

We are concerned that some families, and some older children and teenagers, who do not want to be known to the local authority, may choose not to register with a GP when moving locations or may avoid seeking help from other local health services. Putting their health and wellbeing at risk, to try to avoid local authority engagement. We note that the associated Impact Assessment acknowledges the risk that some families may choose not to register with a GP and outlines how existing guidance would help professionals minimise the possibility of a child going missing from education if they deregistered. However, it does not seem to have addressed the risk that early opportunities to identify safeguarding concerns might be lost, if vulnerable children and young people and their families choose not to register with GP surgeries or to present to hospital for healthcare. It would be helpful, in presenting the case for data on all children to be shared from healthcare settings, to share any evidence that offers professionals reassurance that at risk children or parents of such children who do not show up in healthcare records will be identifiable to other services and that they will have some obligation to encourage them for example to register with a GP. In addition, it is important that if these changes are implemented, they are supported by a public information campaign, with resources for both healthcare professionals and members of the public (addressed to children and also their parents). This will help the public understand why the data is being collected, how it will be used, the methods to keep it secure from inappropriate access, the retention policy and the steps they can take if they have specific concerns (see further details below on transparency).

Transparency

We expect doctors to take steps to ensure patients know what identifiable information about them is being shared with other organisations without their explicit consent; and whether they have control over what is shared or how the information will be used. Doctors will need to be provided with accessible, clear information and materials to be able to explain to children and young people and their parents the purpose of the database, how the information will be collected and used by the LHBs and local authorities, and who they can contact if they have concerns about their details being held on the database. It will be important to maintaining trust in the doctor-patient relationship that doctors themselves have a good understanding of how the data will be collected and used, who will have access it, how long it will be retained. We know that many patients have concerns about who can access their health records in particular settings. In our guidance on Confidentiality, we are clear that doctors must not access a patient's personal information unless they have a legitimate reason to view it (see paragraph 120). We are aware of recent incidents reported in the media where health practitioners have accessed or sought to access medical records inappropriately, and the knowledge that this was possible threatened to undermine public trust in healthcare as a confidential service underpinned by secure systems.

Existing cooperative arrangements for child protection

Lastly, we would reiterate that we support Welsh Government's intended goal to uphold the welfare and safeguarding responsibilities owed to children and young people by ensuring they are receiving an appropriate education. Our own guidance on child protection encourages doctors, as a matter of everyday good practice, to work collaboratively with other agencies to promote the wellbeing of children and protect them from neglect or abuse. We are also aware that there are existing duties to cooperate with local authorities under the Social Services and Well-being (Wales) Act 2014. Section 164 provides that if a local authority requests information from a relevant partner (including local health boards and NHS Trusts), they must provide it unless doing so is incompatible with their own duties or have an adverse effect on its own functions.

This approach encourages and supports cooperation with local authorities, without undermining the duties of confidentiality owed to children and young people. This cooperative approach reflects our own guidance which preserves room for professional judgment on the timing and extent of disclosure of information for safeguarding purposes, in order to do what is in the best interests of the child or young person and uphold their rights.