General Medical Council

GMC Response to the Data Strategy for Health and Social Care consultation

We are grateful for the opportunity to comment on the Data Strategy for Health and Social Care. Some of the questions in the consultation fall outside our regulatory remit or areas of expertise. We have therefore restricted our comments to a specific number of areas. Additionally, our responses do not always lend themselves to the format used in the consultation questions. For these reasons, as well as for ease of reading, we are responding to the consultation in the form of a submission.

The GMC's role and remit

The General Medical Council (GMC) is an independent regulator that helps to protect patients and improve medical education and practice across the UK.

- We decide which doctors are qualified to work here and oversee UK medical education and training. There are approximately 337,000 doctors on the UK medical register. In Scotland, around 23,000 doctors also hold a licence to practise.
- We set the standards that doctors need to follow, and make sure that they continue to meet these standards throughout their careers.
- We take action where a doctor's practice puts the safety of patients, or the public's confidence in the profession, at risk.

Every patient should receive a high standard of care. We help achieve that by working closely with doctors, their employers, and patients, to make sure that the trust patients have in their doctors is fully justified. We expect doctors to be familiar with and follow our ethical guidance and be willing and able to justify any departure from it.

The GMC is not responsible for planning or delivering healthcare services. However, we have an important role in ensuring patient safety, through the professional standards we set for doctors' practice and our quality assurance of medical education and training. Our professional standards, as set out in published guidance, aim to be consistent with UK law and any specific duties that the law requires of doctors.

Response to specific questions

Q7: Thinking about improving the quality of data that is used by health and social care services

In our work as a regulator there are many occasions where we need to combine our data with that of other organisations in order to identify a specific risk, mitigate harm, or decide a course of action. We have 12 active memorandums of understanding in place with other organisations, and 32 active & live data sharing agreements in parallel around this type of activity with teams in place to support.

Based on the experiences of our teams involved in data sharing over several years, there are a range of important factors that tend to come alongside successful endeavours in data sharing:

- There is **trust** in the data provider and data receiver, so they feel confident in sharing the data. The GMC for example needs doctors to trust its handling of their data otherwise it becomes increasingly problematic as an organisation to share, and if sharing such data with others we need to have trust they are capable of and willing to use the data appropriately.
- The existence of the data, and its definitions and plausible value, are **known** by those who can make use of it, so that it is possible to conceptualise its use and therefore put organisational resources into securing it. The GMC tracks over 70 different 'data sharing opportunities', however, the investment of time required to understand what data other organisations hold and whether they are willing or able to share it mean that the cost of exploring the opportunities is prohibitive beyond one or two per year.
- The data owner is **willing and able** to share it. Where organisations see contributing data for wider benefits as valued, either culturally or via statutory legislation, processes are often expedited significantly as it requires effort by the data provider to help the receiver make good use of the data. Many organisations, such as the GMC, who could create benefits from additional data sharing may have no statutory power to compel such data sharing by other organisations, and so rely to some extent upon their goodwill and attitudes to data sharing.
- The data being provided **can be joined up** with other data – i.e. it can be linked to or compared with other, often standardised, datasets. Pooling data requires at least some common & understood definitions, categories, geographic boundaries, time periods, organisations, or similar in order to make best use of it. At the most granular level, unique identifiers that are centrally managed can help, such as organisation codes or person identifiers, as it reduces the effort required to interpret the data significantly.

Regarding the role of the GMC around improving accessibility and quality of data, in our Corporate Strategy 2021-25 we set out our ambitions to enable professionals to provide safe care. One way in which we do this is by analysing data to help identify problems before they become severe, and to identify situations and places where issues are most likely to occur.

Another way in which we do this is by sharing our data for use by others, to manage specific risks such as immediate patient safety concerns, or so that wider benefits like earlier problem identification can be achieved. We share this data in multiple ways each aimed toward different audiences and use cases, so that it is as accessible as it can be for different audiences and purposes. We feel this is both proportionate and justified, and includes the following approaches that increase accessibility:

- Using automated data sharing for all data which can be openly shared, using online 'live data' in an interactive format. All of the GMCs non-sensitive data (i.e., aggregate data with low numbers suppressed) that reasonably would be useful to others is shared via this medium. The GMC do this via our GMC Data Explorer tool which has around 400 quadrillion unique data combinations possible on the first dashboard tab alone, available here. We also provide similar suites of dashboards sharing data from our National Training surveys providing critical data on the quality of medical training environments, available here.
- By maintaining fixed reference data, with consistent layouts, and easy to grasp definitions - aimed at researchers who need referenceable and static data to investigate issues that our data can provide insight into, such as about complaints made to the GMC, the changing composition and location of the workforce, and so forth. These are available in the 'data' section of this page.
- By managing bespoke agreements to share data with other organisations where justified and permissible. This is managed via contractual data sharing agreements, memorandums of understanding, and operating protocols which detail what data will shared, the security controls it will have in place, and the benefits of the sharing.
- By contributing to and managing 'data lakes' which span multiple organisations data and have controlled access supported for researchers who can make use of this more granular data - such as the UK Medical Education Database, or UKMED. Carefully governed access to this controlled data ensures that confidence in the data sharing is maintained, and that the data is used in line with good practice on security, confidentiality, fair use, and within the reasons for which the data was collected.
- By publishing our analysis and understanding of our own data, such as in our flagship publication 'The state of medical education and practice in the UK' or in our series of 'Working paper' publications we help others grasp the relevance of our data to the issues they may also be concerned about, while encouraging them to make contact should they wish to see more or different data that the GMC holds.

Finally, as part of our risk analysis and work to identify and intervene on issues before they become more serious, the GMC makes use of a wide range of data in order to better interpret our own data. When accessing data from outside the healthcare sector, the largest non-health-

sector dataset we use is geographic population characteristic data from ONS, such as deprivation level, gender and age by postcode. These are used by us in several ways, such as helping us understand the types of complaints made about GPs compared to the populations they serve.

Q8: Standards for gathering, storing, and accessing data at a national level

We are supportive of the proposal of the Scottish Government to mandate standards for gathering, storing and accessing data at a national level.

Moreover, it would be beneficial if any standards for data shared for research or analysis purposes were aligned, or at least not disruptive, to those set out by the Office for National Statistics (ONS). The GMC makes extensive use of ONS data and so data that could link to those major national datasets, or that can be interpreted as readily, would be beneficial.

Q9: Data sharing across the system

As with previous points, we support the Strategy's aim to make data more readily accessible across the healthcare system. This can help support patient care in a way that reduces repetition, delay, duplication of effort and opportunities for error.

It is, however, critical that data sharing arrangements do not minimise the importance of a confidential healthcare system or the relationship of trust between doctors and patients that lies at the heart of it.

As expressed on paragraphs 1-8 of our guidance on Confidentiality: good practice in handling patient information outline doctors' common law and professional duty of confidentiality, undermining confidentiality (or appearing to) could adversely affect patients' trust in doctors and the healthcare system more widely, and some individuals and groups may stop seeking medical care or under-report symptoms as a result. This can have adverse implications for the individual and public health.

To make appropriate information sharing the norm we see the key priorities as:

- Putting appropriate legal and ethical structures to foster good practice; and
- Prioritising raising awareness and building public understanding of how their data may be used and what control they have over how and with whom it is shared.

Q12 and Q13: Ethics of data sharing in relation to commercial/research/other purposes

We would like to see the Strategy directly addressing the potential value and importance of anonymised healthcare data, the benefits it can provide to the functioning of the healthcare system and the fact that it will usually be sufficient for purposes other than direct patient care (Paragraph 79 of Confidentiality).

In terms of the data needs and gaps, we have identified that as medical regulator, one key gap in our understanding of the risks and challenges in clinical practice is that we are unable to effectively link, for the purposes of research, the histories and characteristics of patients, clinicians, the location they interacted, and the nature of their interaction. Being able to have governed access to data which allows these key components of healthcare activity would, once used effectively, allow a hugely increased understanding of the challenges faced.

Conclusion

As reflected in our Corporate Strategy 2021-25, we share similar ambitions to other organisations in the health landscape around better collaboration, taking evidence-based decisions, making the best use of data, and understanding the needs of both professionals and patients.

Overall, we are in support of the Scottish Government's vision to make data more readily accessible across the healthcare system as this can help support patient care and experience in a way that reduces repetition, delay, duplication of effort and opportunities for error. At the same it is critical that data sharing arrangements do not minimise the importance of a confidential healthcare system or the relationship of trust between doctors and patients that lies at the heart of it.

As a regulator, we continue to work with other organisations through data sharing and are supportive of the proposal to establish standards for gathering, storing, and accessing data at a national level

We hope these comments are helpful and we would be happy to explore or clarify any aspect of our response with you further.