

Information Standards Board for Health and Social Care

About the ISB

The Information Standards Board for Health and Social Care is responsible to the Department of Health Director of Informatics for the governance and approval of information standards for health and social care in England. It has representation from Intellect (the supplier trade organisation), the regulators, both professional and organisational (e.g. Monitor, Nursing and Midwifery Council, Monitor), NHS organisations and the Association of Directors of Adult Social Services.

An information standard is a formal document approved and issued by the Information Standards Board for health and social care. It defines technical criteria, content, methods, processes and practices for mandatory implementation across health and social care in England. Information standards define how data is managed in a wide range of areas including patient choice, NHS organisation performance and public health.

General Observations

The Information Standards Board (ISB) for Health and Social Care has responded to the consultation in its subject matter area, that of open standards and is supportive of relevant aspects of the policy described in *Making Open Data Real*.

Data is a valuable resource – collecting data carries a cost. Significant investment is made in its collection and maintenance, yet it is rarely managed as a financial asset. Public sector organisations should be required to maintain a data asset register and derive best value from their data, as they would any other asset. In addition, however, this needs to be balanced with the right to privacy and confidentiality of individual data subjects.

The ISB is supportive of the presumption that public sector data should be freely available unless it is protectively marked or contains person identifiable information. The most interesting data tends to be about the citizen. Publication of this data will need strong de-identification systems (technical algorithms, organisational rules, and human behaviours). Providers collecting data that will be published (as specified in their information standard) need to ensure that their communication products alert citizens to the potential uses of their data; and to manage objections and the withholding of consent where this is the basis for processing.

Success is predicated on good data quality. This must form part of any proposal. Published data should be accompanied by metadata describing its provenance and data quality.

The right to data should be exercised alongside existing data rights including those of the Data Protection Act 1998 and the Freedom of Information Act 2000. As such, the Information Commissioners Office is well placed to police this right and ensure it remains compatible with existing information legislation.

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Setting Open Data Standards

Open standards are crucial to the delivery of open government. Unless there is commonality across data it cannot be readily used. In order for data to be useful it needs to be accompanied by a data dictionary describing how it was collected, its structure, any dependent standards (e.g. it may be encoded in DOCX format or rely upon an ISO coding system) and other related information. Without this the data is meaningless. Where appropriate this description should be standardised.

It has been said “standards are great, there are so many to choose from.” If the public sector is to deliver benefit from open data it needs to select the standards to be used. This should be done in a transparent manner supported by evidence of business benefit. The decision should be made using evidence that the standard is useful, fit for purpose, implementable and capable of delivering the stated benefits.

Standards need to be set at the appropriate level, whether that is international, government or departmental. If international, the UK needs two safeguards: one is continued use beyond licensing period of data already collected and second is a say in governance arrangements of said standard. This includes the use of standards developed by ISO and CEN.

There is a need for a cross-government open standards board to consider whether it is appropriate to set cross-public sector standards while respecting the requirement for individual government departments to set their own standards that do not apply across the public sector, e.g. health specific. If standards are applied too widely or too rigorously they can stifle innovation. Such a Board would therefore need to be composed of representatives from across the public sector to ensure that standards are not imposed inappropriately where they do not apply to a specific sector.

Where possible, existing standards should be adopted or adapted rather than developing a new one. Only in very specific cases should a standard be developed from scratch. That said, the experience from the English NHS is that international standards are rarely suitable off the peg. They instead need to be adapted to the needs of UK business. In order to be useful the standard (known as an information standard in the NHS) needs to include the data structure and model, links to reference data (e.g. common organisation codes), evidence of testing and implementation guidance. The public sector has a useful role to play in developing and maintaining these standards.

The development or adaptation of standards should follow a documented methodology to ensure that the final product is of sufficient quality. The ISB uses the [information standards development methodology](#) based upon software engineering good practice.

Examples

- ISB 0095 18 [Referral to Treatment Waiting Times](#) mandates how data should be collected on the time taken from referral by a GP to treatment in an acute

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hospital. This information is published on the NHS Choices website, supporting patient choice.

- ISB 0090 [Organisation Data Service](#) specifies reference data for all NHS organisations including their name and a system code. The system code is used across all data sets to make sure that an organisation can be uniquely referenced.
- ISB 1573 [Mixed-Sex Accommodation](#) specifies a small data set which hospitals report to the Department of Health. This ensures that the Minister's policy is being delivered.

Further Information

For further information on the work of the ISB, please see www.isb.nhs.uk.