



The ROYAL COLLEGE of
OPHTHALMOLOGISTS

Ophthalmic Services Guidance

Healthcare Informatics

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1 Introduction

Healthcare involves the collection and generation of huge amounts of information which is subsequently managed, utilised and shared. Healthcare informatics is the science of ensuring that this processing of information is efficient and safe for the benefit of patients. With the current rapid improvements in information technology, it is the duty of healthcare providers to harness this technology to maximise efficiency, safety and quality of patient care, as well as to help drive healthcare innovation.

This document intends to provide a glossary and basic introduction to the multiple facets of healthcare informatics and provides references for further reading.

2 NHS Digital

NHS Digital, previously called HSCIC (Health and Social Care Information Centre) is an executive non-departmental public body set up by the Department of Health to provide national information, data and IT systems for health and care services. Statutory duties of NHS Digital include: collecting and publishing health and care information, providing national technology for health and care services, producing information standards, improving the quality of health and care information and data, publishing national indicators for health and care, giving advice and support to health and care organisations on information and cyber security, and providing the Information Governance Toolkit for care organisations to assess how well they are handling information and data.

3 Public Health England (PHE)

PHE is an executive agency of the Department of Health established in 2013 to bring together public health specialists from more than 70 organisations into a single public health service. It has a mission to protect and improve the public's health and reduce inequalities. PHE has a role in sharing indicator data across a range of health and wellbeing themes ([Public Health Profiles](#)), supporting the NHS Digital [Joint Strategic Needs Assessment](#). Additionally, PHE run the [National Cancer Registration and Analysis Service](#) (NCRAS).

4 Clinical activity coding

All clinical activity in the NHS is reported in some way. The patient's inpatient or daycase diagnosis is recorded using the international standard ICD-10 (International Classification of Diseases). Any procedure is recorded using OPCS-4 (Office Population Census and Statistics), a UK classification developed and maintained by the Clinical Classifications Service at NHS Digital. The RCOphth has been involved in developing OPCS-4 and the most recent version (OPCS-4.8) was implemented in April 2017. The ICD-10 diagnosis and OPCS procedure codes feed into a system that groups episodes of care into Healthcare Resource Groups (HRGs). The National Casemix Office (NCO) at NHS Digital is responsible for developing and maintaining the HRG classification and for developing the "grouper" software used by the service to group patient activity to HRGs. The NCO is continually refining the HRG design with input from the

clinical community, typically through the NCO Expert Working Groups (EWGs). The RCOphth is represented on the Ophthalmology EWG. The latest iteration of the HRG classification is known as HRG4+, and it has been used to collect reference costs since the Reference Costs 2014/15 collection (HRG4+ was phased in over three reference cost collections, from 2012/13 to 2014/15) and for payments since April 2017.

NHS England and NHS Improvement have joint responsibility for national pricing. The published 2017/18 and 2018/19 prices are based on the national reference costs for 2014/15; however, for various reasons, including policy requirements, national prices are often very different to the reference costs they are based on. While HRGs are the currency for both reference costs and payment, reference costs are collected at the episode level whereas prices are set at the spell level (covering the full period between patient admission and discharge). The national prices published by NHS Improvement are base prices. All providers in England (except for Cornwall, which has a Market Forces Factor (MFF) of 1) will receive more than the base price. The final price is dependent on the specific provider's MFF.

There is a move towards "best practice tariffs" (BPTs), which are intended to remunerate an entire care pathway rather than individual visits. A cataract BPT was one of the first of these to be introduced in 2010. However, the cataract BPT has been retired as of 2017/18 after being non-mandated for several years. The only ophthalmology BPT in national pricing in 2017/18 and 2018/19 is BP66 Dacryocystorhinostomy including insertion of tube.

5 Electronic prescribing, discharge and outpatient letters

The Electronic Prescription Service (EPS) enables prescriptions to be sent electronically from a General Practice surgery to a pharmacy of the patients' choice and then on to NHS Prescription Services for payment. The [dictionary of medicines and devices \(dm+d\)](#) is a reference dictionary of descriptions and codes which represent medicines and devices in use across the NHS. Information in the dm+d includes current and discontinued products and packs available from manufacturers and the indicative price of each pack of a product.

A patient safety alert published by NHS England in 2014 identified that a third of patient safety incidents reported to the National Reporting and Learning System (NRLS) were directly related to poor communication at the point of discharge. Since October 2015, organisations have been required to use either secure email or direct electronic transmission to send and receive discharge summaries.

The Professional Record Standards Body for health and social care (PRSB) is conducting a project developing national outpatient letter standards, including a requirement for electronic communication. NHS Digital will develop technical specifications for this by January 2018 and implementation through the NHS standard contract will be required by October 2018.

6 N3 Network / Health and Social Care Network (HSCN)

N3 is the current national broadband network that connects NHS organisations and was designed primarily for NHS providers to access national applications. The N3 network programme is due to be phased out in March 2017 and replaced by the Health and Social Care Network (HSCN) programme. N3 is delivered by a single supplier on a long-duration contract, whereas HSCN is a standards based network that will enable multiple suppliers to form a marketplace of HSCN certified services, thereby allowing health and social care providers choice in terms of the best fit for them. The HSCN is designed to enable interoperability between NHS and non-NHS health and social care organisations which may facilitate connectivity between optometric practices and NHS organisations.

7 NHS e-Referral Service

The NHS e-Referral Service is replacing the current Choose and Book system which combines electronic appointment booking with patient choice for the place, date and time for first hospital or clinic appointments. The appointment may be booked in the GP surgery at the point of referral, or later at home by phone or online. This service is intended to provide greater flexibility with 'any to any' referral functionality.

8 NHSmail

NHSmail is the secure email service available for use across health and social care organisations. The service securely connects health and social care professionals to enable efficient patient care.

9 Big Data

In the current digital age, the quantity of data produced is growing exponentially. Massively increasing numbers of sensors and smart devices together with everyday online interaction has led to a tsunami of data. 90% of the data in the world today was generated in the last two years. Big data is defined by the volume, velocity and variety of data (known as the 3 Vs of Big Data) being produced together with new methods for storing, accessing and analysing the data. Big data is already revolutionising politics, business strategy and social interaction, and has huge potential to improve health care.

10 Structured and unstructured data

Structured data has a high level of organisation and is in a format which can be easily coded, categorised and searched for, facilitating analysis and potential combination with other data sources. An example would be electronic questionnaire data where answers were required to be selected from a drop-down list of potential options. Unstructured data does not follow a fixed or pre-specified format and is harder to code or categorise without further processing. An example would be data collected in free-text boxes of a questionnaire.

Examples of structured data:

- Electronic medical records
- Electronic medication prescriptions
- Electronic laboratory reports
- Facebook friends, twitter hashtags

Examples of unstructured data:

- Paper clinical notes
- Medication actually taken
- Free text radiology reports
- Facebook posts, tweets
- Scanned documents, PDFs of handwritten clinical documentation

11 Real World Evidence

Real world evidence (RWE) relates to the findings of studies utilising real world data (RWD) as opposed to data collected in protocolled lab or hospital based studies. RWD is collected routinely as part of usual health care processes on an observational, naturalistic, non-interventional basis. Advantages of RWE include the rapid availability of data, the volume of data that are within reach, the low cost, and that the evidence is directly relevant to everyday practice. However, RWE is vulnerable to bias and confounding that may be mitigated by well-designed, protocolled or randomised studies. Additionally, RWD practitioners have to deal with missing data and data quality issues as well as some degree of variation in routine practice that is always difficult to account for.

There is a growing necessity to monitor the effectiveness of health care using RWD given the availability of data and the relatively low costs involved. Future possibilities include the requirement for pharmaceutical companies to demonstrate product effectiveness using RWD before receiving payment, so called “value based prescribing”. RWD is also helpful for setting standards, benchmarking and audit. The RCOphth National Ophthalmology Database is an example of an initiative utilising RWD.

12 Caldicott Report

The Caldicott Report was published in 1997 following a review commissioned by the Chief Medical Officer of England and chaired by Dame Fiona Caldicott, the National Data Guardian for Health and Care. The review addressed the ways in which patient-identifiable information was handled in the NHS. The Caldicott Report put forward six key principles:

- i) justify the purpose for every flow of patient identifiable information,
- ii) do not use patient identifiable information unless it is necessary,
- iii) use the minimum necessary patient-identifiable information,
- iv) access to patient identifiable information should be on a strict need-to-know basis,
- v) everyone with access to patient identifiable information should be aware of their responsibilities,
- vi) understand and comply with the law

A [follow-up report](#) in 2013 added a further principle: vii) the duty to share information can be as important as the duty to protect patient confidentiality. The report provides guidance and recommendations for maintaining the rights of patients while not hindering effective patient care or medical research. The latest [review and public consultation](#) of consent and opt-outs by the National Data Guardian suggests that patients are automatically opted in to share their data but can elect to opt out of their data being used for audit, service evaluation and research (secondary use) but not for direct care (primary use). The [national data opt-out](#) was introduced in May 2018 and, by 2020, all health and care organisations will be required to apply national data opt-outs.

Multiple organisations are engaging the public to improve confidence in how patient data is used and the potential benefits to health care that can be achieved with appropriate use of data. For example, the Wellcome Trust have established an independent taskforce on the use of patient data, and the Association of Medical Research Charities have published a booklet [A matter of life and death: how your health information can make a difference](#). The [#datasaveslives](#) campaign was launched in 2014 to highlight the positive impact that data-led research can have on public health.

13 Section 251

Section 251 of the NHS Act 2006 allows the common-law duty of confidentiality to be temporarily lifted so that confidential patient information can be legally transferred to an applicant. The activity must be for a medical purpose (including medical research with ethical approval and the management of health care services), in the public interest or in the interests of improving patient care, compliant with the Data Protection Act 1998, and undergo annual review to demonstrate whether continued support is required.

Section 251 applications require robust evidence for why the temporary lift of the duty of confidentiality is required and what the benefits will be. An application cannot be used to override existing patient consent. Section 251 has been instrumental in the development and ongoing practice for cancer registries. This is because anonymised information will not fulfil the purpose of a cancer registry and it is impractical to seek explicit and informed consent from every cancer patient. Refusal of consent by a critical mass of patients would also have a detrimental impact on the studies possible from each registry.

14 General Data Protection Regulation

The European Union (EU) General Data Protection Regulation (GDPR) came into force in May 2018 and is not contingent on the status of the UK in the EU. This new legal framework for data protection has similarities with the previous UK Data Protection Act 1998 and some new and different regulations. The [Information Commissioner's Office](#) (ICO) have published a regularly updated [overview of the GDPR](#), and UK universities and institutions have been developing their own local interpretation and application of GDPR and training their employees accordingly. A summary of some of the key aspects of GDPR is given here.

GDPR applies to any [personal data](#); this includes pseudonymised data which can be indirectly linked to an individual using an identifier (e.g. a hospital number). The GDPR principles for processing personal data are largely similar to those in the Data Protection Act 1998. A much-publicised new stipulation is the '[right to be forgotten](#)' which gives individuals the right to have personal data erased.

Organisations that process large amounts of data or special categories of data (such as genetic data) are required to appoint a Data Protection Officer (DPO). The responsibilities of DPO include informing and advising the organisation and its employees about their obligations to comply with the GDPR and to monitor compliance with the GDPR. There is now an obligation for organisations to demonstrate they have considered and integrated data protection for all personal data processing activities. Data protection needs to be considered from the earliest stages of project development – 'privacy by design'. [Data Protection Impact Assessment](#) (DPIA) is a process to help organisations identify and minimise the data protection risks of a project. There is now an increase in potential fines for organisations that fail to comply with GDPR (€20 million or 4% of global gross revenue).

15 Interoperability within and between healthcare organisations

Multiple different computer systems exist within healthcare providers, such as patient administration systems, electronic health records, and billing systems. For an organisation to work effectively, these different systems should be able to communicate to each other and interface. [Health Level 7 \(HL7\)](#) is a set of standards, formats and definitions for transfer of clinical and administrative data between software applications used by different healthcare organisations. One such standard is the Clinical Document Architecture (CDA) which is a process by which clinical documents such as discharge summaries and progress notes are communicated between software systems.

Fast Health Interoperability Resources (FHIR) is a draft standard that has been derived from HL7 to support the exchange of structured data between electronic medical records. It includes an API (Application Programming Interface) which makes use of modern web-based technologies to facilitate data exchange.

Mobile applications can connect to larger, hospital data systems using HL7 based tools such as SMART on FHIR. Digital Imaging and Communications in Medicine (DICOM) is a standard for handling, storing, and communicating information in medical imaging. It includes a file format definition and a network communications protocol. DICOM allows the integration of multiple medical imaging devices by different manufacturers into one over-arching system.

As well as interoperability between computer and imaging systems, ultimately, healthcare professionals need to be able to communicate with each other using a common language. [SNOMED CT](#) (Systematized Nomenclature of Medicine - Clinical Term) is a clinical reference terminology that codes the content of health information (including diagnosis, clinical findings, symptoms, procedures, organisms, medications) to allow effective recording and communication of data. The [Human Phenotype Ontology](#) (HPO) aims to provide a standardised vocabulary of phenotypic abnormalities encountered in human disease. The [International Consortium for Health Outcomes Measurement](#) (ICHOM) is a non-profit organization founded by individuals from Harvard Business School, the Karolinska Institute and the Boston Consulting Group. The purpose of the organisation is to transform health care systems worldwide by measuring and reporting patient outcomes in a standardised way.

16 Genomics and other ‘omics’

The big data explosion is also occurring in the biological sciences. Previously unavailable large-scale and comprehensive data sets are driving fields of science which are developing new analytical methods to mine the data and drive novel insight. Example emerging fields include genomics, proteomics and metabolomics. Collectively, these large data-driven fields are termed “omics”.

Genetic research has been revolutionised in the last decade with the dramatic reduction in cost of genotyping (determining the genetic code of individuals). It has now become affordable to study the whole human genome in relation to disease (i.e. rather than examining one candidate gene and testing one a priori hypothesis at a time, an exploratory examination of the whole genome in relation to disease is now possible and can generate multiple novel hypotheses). The first new discovery from such a study (a genome-wide association study – GWAS) was the identification of the association between complement factor H and age-related macular degeneration.

Genotyping is no longer limited to research studies as it is now affordable and accessible for members of the public to test their whole genome. The commonest platform for the public to test their own genetic code and interpret it is provided by 23andMe, and it remains to be seen how this data may feed into current health care systems to improve care. The research branch of 23andMe, with participant consent, has identified many previously unknown myopia-associated genes.

17 Deep learning

Deep learning, machine learning and neural networks are all terms used to describe machine-driven analysis of large-scale data to uncover patterns that may not have otherwise been apparent using conventional human-driven analysis. Such approaches have revolutionised fields such as automated speech recognition. The field is emerging in medical sciences and within ophthalmology, including a recently announced collaboration between Google Deep Mind and Moorfields Eye Hospital. The discipline of deep learning originated from a desire to develop artificial intelligence (AI). Over time, researchers realised that they could mimic specific functions led by different areas of the human brain with mathematical algorithms and statistical models.

18 National Ophthalmology Database Audit

The RCOphth has been commissioned by Health Quality Improvement Partnership (HQIP) to manage the National Ophthalmology Database (NOD) Audit as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

The NOD Audit will prospectively collect, collate and analyse a standardised, nationally agreed cataract surgery dataset from all centres providing NHS cataract surgery in England and Wales to update benchmark standards of care and provide a powerful quality improvement tool. In addition to cataract surgery, electronic ophthalmology feasibility audits will be undertaken for glaucoma, retinal detachment surgery and age related macular degeneration AMD.

Building on the achievements of the RCOphth NOD Project, the audit will utilise validated and risk (case complexity) adjusted measures of quality which discriminate between centres and surgeons. Initially these will be based on legacy (historic) EMR data up to 2014. All EMR databases with national dataset compliant data will be eligible for data submission. The prospective phase of the audit commenced data collection in September 2015, following provision of data collection tools for participating centres. These included a web based tool for optometrists to return visual acuity and refractive data. Relevant aspects of the audit will be submitted for peer reviewed publication in medical journals.

Following appropriate local information governance permissions, data from electronically enabled units are remotely extracted to a secure server within the NHS firewall. Paper based units are also able to submit a minimum dataset via a data-entry spreadsheet completed manually. Data are pseudonymised, checked for errors as far as possible and descriptive analyses produced. Summarised data are presented on the audit website, www.nodaudit.org.uk such that contributors are able to view data from their own centre in the context of aggregated data from all centres. Contributors are also able to use these data for personal audit with benefits in terms of appraisal and revalidation. As of 2017 named independent surgeon and centre cataract surgery results will become available in the public domain.

For more information, please visit www.nodaudit.org.uk or contact the Professional Standards Department via noa.project@rcophth.ac.uk

19 Further reading

1. NHS Digital - <https://www.digital.nhs.uk/>
2. Public Health England (PHE) - <https://www.gov.uk/government/organisations/public-health-england>
3. PHE Public Health Profiles - <http://fingertips.phe.org.uk/>
4. Joint Strategic Needs Assessment - <http://content.digital.nhs.uk/jsna>
5. The National Cancer Registration and Analysis Service - <http://www.ncras.nhs.uk/>
6. The Dictionary of medicines and devices (dm+d) - <https://www.nhsbsa.nhs.uk/pharmacies-gp-practices-and-appliance-contractors/dictionary-medicines-and-devices-dmd>
7. To Share Or Not To Share? The Information Governance Review (Caldicott review follow-up report) - <https://www.gov.uk/government/publications/the-information-governance-review>

8. Review of data security, consent and opt-outs - <https://www.gov.uk/government/publications/review-of-data-security-consent-and-opt-outs>
9. Association of Medical Research Charities: A matter of life and death - <http://www.amrc.org.uk/publications/a-matter-of-life-and-death-how-your-health-information-can-make-a-difference>
10. Datasaveslives campaign - <https://www.herc.ac.uk/get-involved/data-saves-lives/>
11. OPCS, ICD-10, clinical classifications standards
<https://digital.nhs.uk/article/1117/Clinical-Classifications>
12. HRG classification, HRG groupers, HRG4+, Casemix Companion - <http://content.digital.nhs.uk/article/7500/HRG4-201718-Consultation-Grouper>
13. National Casemix Office HRG groupers documentation - <http://content.digital.nhs.uk/casemix/downloads>
14. Department of Health's NHS Reference Costs for 2015/16 - <https://www.gov.uk/government/collections/nhs-reference-costs>
15. National Tariff Payment System, Best Practice Tariffs and Market Forces Factors, national prices for 2017/18 and 2018/19 - <https://improvement.nhs.uk/resources/national-tariff-1719/>
16. Human Phenotype Ontology - <http://human-phenotype-ontology.github.io/>
17. International Consortium for Health Outcomes Measurement (ICHOM) - <http://www.ichom.org/>
18. Health Level 7 (HL7) - <http://www.hl7.org.uk/>
19. SNOMED CT - <http://www.snomed.org/snomed-ct>
20. Overview of the General Data Protection Regulation, Information Commissioner's Office - <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/>
21. Information Governance Alliance (IGA) - <https://digital.nhs.uk/information-governance-alliance>
22. National Ophthalmology Database Audit - www.nodaudit.org.uk

EXTRA LINKS:

National Data Opt-Out - <https://digital.nhs.uk/services/national-data-opt-out-programme>

ICO Guide to the GDPR - <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/>

ICO Overview of the GDPR - <https://ico.org.uk/media/for-organisations/data-protection-reform/overview-of-the-gdpr-1-13.pdf>

ICO Personal Data - <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/>

Data Protection Impact Assessment - <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/accountability-and-governance/data-protection-impact-assessments/>

GDPR Right to Be Forgotten - <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-erasure/>

20 Author

Mr Anthony Khawaja on behalf of the Informatics and Audit Sub-committee