With the established success of the National Joint Registry and the emergence of a range of new national initiatives for the capture of electronic data in the National Health Service, orthopaedic surgery in the United Kingdom has found itself thrust to the forefront of an information revolution. In this review we consider the benefits and threats that this revolution poses, and how orthopaedic surgeons should marshal their resources to ensure that this is a force for good.

Sources of data
A wealth of valuable national electronic resources is available to the orthopaedic surgeon (Table I), many overlapping considerably with locally kept datasets, often without any clear relationship between them.

In the United Kingdom a considerable amount of data is captured routinely in the NHS. Every admission to an NHS hospital requires the central return of a clinical dataset. These data are normally captured using the Trust's patient administration system (PAS) and is submitted via a British Telecom database called Secondary User Services. The NHS Information Centre extracts and cleans the data, making them available in an anonymised format for further analysis by users and third parties as the Hospital Episode Statistics (HES) database.

HES captures inpatient diagnostic and procedure codes, but outpatient collection is not mandated, and so few Trusts submit these data. Consequently, data from outpatient consultations are not available for resource or service planning. For example, although we have accurate data on the number of knee replacements performed, we do not know how many patients are diagnosed with early arthritis in the outpatient setting (the demand incidence), which may be several years prior to their eventual knee replacement. In the near future outpatient clinical coding is likely to become obligatory.1

Other national datasets have emerged through the need for surveillance. Joint registries are prospective audits that allow tracking of implants and related patient outcomes. The first national joint registers were started in 1975 in Sweden for knee replacements2 and in 1979 for hip replacements.3 In the United Kingdom a regional register for hip and knee replacements was introduced in Trent in 1990.4 In 2002 the National Joint Registry (NJR) was established in England and Wales after an enquiry into the failure of the 3M Capital Hip (3M Health Care Ltd, Bracknell, United Kingdom).5 Initially participation was voluntary, but it is now mandatory for NHS hospitals in England and Wales. In 2010 the NJR achieved its one millionth record and is now the largest joint register in the world. Data from joint registries have made an important contribution to identifying poor performance, and a number of implants have since been withdrawn from the market either voluntarily or compulsorily. An example is that of the Articulating Surface Replacement (ASR) hip (DePuy Orthopaedics Inc., Warsaw, Indiana), which was withdrawn in 2010 following a device alert by the Medicines and Healthcare products Regulatory Agency (MHRA).6

The National Hip Fracture Database (NHFD) is another example of a successful United Kingdom orthopaedic register (Table I). During the first four years of the NHFD, real-time feedback from continuous audit has driven huge improvements in patient care and also led to changes in national policy.7 Hip fractures became one of the first national quality...
standards selected by the Department of Health’s Best Practice Tariff initiative, in which additional payments are offered to hospitals for meeting agreed quality standards (Table II).

<table>
<thead>
<tr>
<th>Data</th>
<th>Population</th>
<th>Description</th>
<th>Approximate size in March 2011</th>
<th>Data owner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Episode Statistics (HES)</td>
<td>Every admission to an NHS hospital</td>
<td>The dataset includes demographic information as well as diagnostic and intervention codes. The diagnostic information is classified using the World Health Organization (WHO) International Classification of Diseases version 10 (ICD-10) and intervention classified using Office of Population Censuses and Surveys Classification of Surgical Operations and Procedures version 4.5 (OPCS-4.5). At present only inpatient data are normally captured</td>
<td>287 million inpatient finished consultant episodes (FCEs)</td>
<td>Department of Health (DH) (NHS Information Centre)</td>
</tr>
<tr>
<td>National Joint Registry (NJR)</td>
<td>All elective hip and knee joint replacements in England and Wales since 2002; ankle replacements included; shoulders and elbows to be included in 2012</td>
<td>Procedure and implant details; endpoint is revision; linked to HES database. The NJR is overseen by the NJR Steering Committee including clinicians, industry, NHMS management and other representative stakeholders. The service is provided by the Healthcare Quality Improvement Partnership (HQIP) on behalf of the DH</td>
<td>1.2 million records</td>
<td>DH (HQIP)</td>
</tr>
<tr>
<td>Patient Reported Outcome Measures (PROMS)</td>
<td>All elective hip and knee joint replacements in England and Wales since 2010</td>
<td>Oxford hip and knee scores and EuroQol quality of life score (EQ5D) are captured pre-operatively and after six months by patient-completed questionnaires. Longer-term follow-up is also now taking place</td>
<td>200 000 records</td>
<td>DH</td>
</tr>
<tr>
<td>General Practice Research Database (GPRD)</td>
<td>Primary care patients representing about 8% of the population (625 General Practices)</td>
<td>Primary care diagnoses (captured as READ Codes) from 625 practices, generalisable nationally. The GPRD is run by the Medicines and Healthcare products Regulatory Agency (MHRA)</td>
<td>Over 11 million research-useable number of persons</td>
<td>DH (MHRA)</td>
</tr>
<tr>
<td>Surgical Site Infection Surveillance Service Database (SSISS)</td>
<td>All hip and knee replacements, reduction of fractures of long bones, and spinal surgery, in participating hospitals</td>
<td>In April 2004 surveillance of SSI in orthopaedic surgery became mandatory for all English NHS Trusts. Active monitoring takes place post-operatively while in hospital as well as post-discharge surveillance for 30 days (or one year if an implant is used). Inpatient data are mandatory. Outpatient data are not mandatory</td>
<td>541,619 orthopaedic operations were surveyed. 5,577 inpatient and re-admission SSIs were reported</td>
<td>DH (Health Protection Agency)</td>
</tr>
<tr>
<td>Venous Thromboembolism Registry</td>
<td>Patients with suspected thromboembolism from contributing hospitals</td>
<td>An industry-sponsored national venous thromboembolism (VTE) registry. Seven hospitals participated in the ongoing PUSH study (Prospective Follow-Up Survey in VERITY Hospitals). Contributing centres provide data, which is compared regionally and nationally</td>
<td>They claim that they will cover more than 100,000 suspected VTE events spanning the period 2002 to 2012</td>
<td>Sanofi-Aventis (Guildford, Surrey, United Kingdom)</td>
</tr>
<tr>
<td>National Hip Fracture Database (NHFD)</td>
<td>Patients with a fractured neck of femur from 191 participating hospitals</td>
<td>The NHFD was launched in 2007 as a joint venture between the British Geriatrics Society and the British Orthopaedic Association. It is run as a National audit project and comes under the auspices of the Healthcare Quality Improvement Partnership (HQIP)</td>
<td>132,000 records</td>
<td>DH (NHS Information Centre) (IC)</td>
</tr>
<tr>
<td>London Implant Retrieval Centre (LIRC)</td>
<td>Patients with failed metal-on-metal hip components</td>
<td>The LIRC was set up in 2008 as a research collaboration between Imperial College London and the Royal National Orthopaedic Hospital, Stanmore. Funding sources include the British Orthopaedic Association through an industry consortium of nine manufacturers. Its aim is to better understand the variables that affect outcome for metal-on-metal hip prostheses.</td>
<td>1250 failed metal-on-metal hip components</td>
<td>LIRC, Imperial College London, and Royal National Orthopaedic Hospital</td>
</tr>
<tr>
<td>UK Biobank</td>
<td>General population</td>
<td>The UK Biobank was funded by the Wellcome Trust, Medical Research Council and the DH, at a cost in excess of £45 million over ten years, to collect tissues (e.g., blood and buccal swabs) alongside demographic and other information relating to the patient. It was set up as an open resource for any investigators around the world that wish to carry out research using the samples collected</td>
<td>500,000 people aged 40 to 69 years from across the UK</td>
<td>UK Biobank (Registered Charity)</td>
</tr>
<tr>
<td>Stanmore Musculoskeletal Biobank</td>
<td>Collects blood, urine, saliva and normal and diseased tissue (bone, cartilage and muscle) donated from patients attending various hospitals</td>
<td>An NREC (Ethics) approved facility at the Royal National Orthopaedic Hospital in Stanmore, United Kingdom. Focuses on musculoskeletal diseases such as arthritis, spondylosis and bone and soft-tissue tumours and is a large contributor to the Wellcome Trust Sanger Institute, which is leading the International Cancer Genome Project (ICGC) bone tumour project.</td>
<td>4400 matched tissue samples (normal and pathological specimens from the same patient)</td>
<td>University College London and Royal National Orthopaedic Hospital</td>
</tr>
<tr>
<td>INBANK</td>
<td>Primary and secondary care data from a variety of sources</td>
<td>Arthritis Research UK aims to develop a national platform of clinical data, and patient reported data, all linked to a central biobank archive of stored biological samples. This central resource (INBANK) will provide access for recruitment to clinical studies and also link to follow up morbidity data to assess both clinical benefit and adverse events following treatment</td>
<td>In set-up</td>
<td>Arthritis Research UK (AR-UK)</td>
</tr>
</tbody>
</table>
The addition of material or tissue samples to data collection to create biobanks generates even more exciting potential for the datasets (Table I).

**Data quality**

Both the NJR and the NHFD have generally been positively received by orthopaedic surgeons. However, as the net of electronic data spreads, both the completeness and the accuracy of the data have come to the fore as critical determinants of the value of these datasets.

Currently, clinical information is coded using the International Classification of Diseases version 10 (ICD-10) and the Office of Population Censuses and Surveys Classification of Surgical Operations and Procedures version 4.5 (OPCS-4.5). These are complex systems that are not easy to use. A potential solution to the difficulties encountered with clinical coding might come from the introduction of a simpler system that uses intuitive diagnostic and procedure terms that are more familiar to the clinician.

Systematised NOmenclature of MEDicine – Clinical Terms (SNOMED-CT) is a system that aims to describe accurately all medical conditions and procedures using terms that we might use on a day-to-day basis. Because SNOMED-CT is to be mapped to the existing coding systems, data could be generated automatically without the need for coding to take place.

Currently SNOMED-CT is not widely implemented in secondary care; however, this situation is changing, being driven by the World Health Organization, which is in the process of developing a revised coding classification (ICD-11) for publication by 2014.

HES data cover every inpatient episode, and linkage with other datasets can allow sophisticated approaches to case-mix adjustment. NHS Trusts rely on clinical coders to extract information from unstructured medical records, and although this professional group has considerable expertise, selection of the most clinically appropriate codes requires close contact with clinicians. Unfortunately, in most NHS Trusts this is rarely achieved.

One of the many uses of Trust data is the generation of Healthcare Resource Groups for payment by results. Unfortunately, in general payment by results has not improved the accuracy of coding, and in most practical situations orthopaedic surgeons might find it difficult to access data in a meaningful way without significant coding input.

**Making sense of the data**

Along with the need for accuracy and completeness in data collection is the requirement to analyse and present data in an appropriate and understandable way. Analytical studies need to use methods that provide an understanding of whether observations might have arisen by chance or through bias (for example through the influence of case-mix). This may require linking to other patient-related information and the use of statistical methods to allow adjustments and estimations of statistical significance.

The complexity and limitations of analysing data on this scale are illustrated in the recently published Patient Reported Outcome Measures (PROMs) project. The project evaluates four conditions: hip and knee replacements; varicose veins; and groin hernias (Table I). The methodology requires linkage to HES to allow operation date and provider to be validated, and for risk adjustment. To date, the analysis has indicated that all institutions demonstrate a statistically significant health gain, as measured by improvements in patients’ clinical scores and quality of life measures six months after surgery. A similar result has been obtained from the analysis of PROMs data one year after hip replacement in Sweden. In the United Kingdom detailed analysis focusing on the health gain between institutions and between procedures is difficult. In the first instance, differences between institutions are difficult to interpret because numbers are small and confidence intervals are wide. Poor-quality care may not be reliably detected by identifying statistical outliers even after case-mix adjustment, as there can be many other valid reasons for such results. Secondly, it is challenging to present the data to the public in a way that will enable them to exercise choice. Presentations that show statistically significant outliers, such as funnel plots, are hard to interpret. League tables that rank providers are attractive because of their simplicity, but can be very misleading. It is natural to assume that number 1 in the list is better than number 21, but the difference may simply be due to random variation.

Interpretation of the quality of life scores (such as the EuroQol (EQ-5D)) is not straightforward, and too simple an analysis might also be misleading. A procedure undertaken early in the course of a disease may show little health gain, but few data are available to evaluate the impact of delaying the procedure until the patient is severely affected. Indeed, Swedish data for hip replacements suggest that Charnley category C, male gender and greater age are associated with less improvement in health-related quality of life.

In addition, ceiling effects for the clinical scores may mask improvements undetected by the test. This is not to undermine the value of the PROMS data, which are an extensive asset to the orthopaedic community for...
evaluating outcomes, but is an indication of the need to avoid simplistic approaches to interpretation and reporting. For example, a recent article in the Health Service Journal suggested that money could be saved by preventing operations that provided no health gain to patients. This is a stance vociferously refuted by the British Orthopaedic Association, which argues that ‘Health authorities are “cynically” misusing surgery data to put people off having hip and knee replacements’.

The difference of opinion arose because general health measures (EQ-5D) were reported in preference to clinical scores (Oxford hip and knee scores). The former showed lower rates of improvement compared with the latter. It is this form of selective use of statistics that is potentially harmful to the profession and to patient care.

**Discussion**

When considering an elective intervention, two questions are important to the patient: ‘What sort of outcome can I expect from this procedure?’ and ‘Where is the best place to go for the optimal outcome?’ At present the answers to these two questions are nearly impossible to find.

A recent consultation from the Department of Health, ‘Liberating the NHS: An Information Revolution’, proposes transparency and access to data in the belief that it will improve quality, reduce variability and improve equity.

There is no doubt that good-quality data can improve care, as demonstrated by the cardiac surgeons from England who now boast one of the lowest mortality rates for cardiac surgery in Europe.

In the near future it is possible that regulators may elect to try to loads of a particular procedure are insufficient, or those whose outcomes for certain procedures are below acceptable standards. Indeed, the process of revalidation may drive the less common procedures into the hands of a small number of individuals with a large enough caseload to deliver the best results. It will of course be up to the profession to ensure that such decisions are appropriate, and not made on inaccurate and incomplete data.

Although there is a compelling case for electronic data collection, experience to date suggests that the process needs to be tempered with caution and that the right design for the system is crucial. A common thread among information technology (IT) projects in health has been their combination of ambition and limited appreciation of scale. This has perhaps been most apparent in the United Kingdom’s £11.4 billion National Programme for IT, later renamed Connecting for Health.

In 2002, the intention was for each NHS patient to have a summary care record containing limited but key medical information, such as major diagnoses and allergies, and a detailed care record containing their comprehensive medical history and treatment. By 2010 these records were to have been fully implemented and accessible across primary and secondary care to those who needed them.

It is disappointing that the ambition of the project was not matched by delivery. In 2011 the National Audit Office concluded that the programme, as initially conceived, will now never be delivered. Nevertheless, the programme has resulted in a broadband network and a system to share radiographs electronically, and now a local approach to development has been adopted allowing NHS organisations to introduce smaller, more manageable systems that meet their local needs.

**Practical implications**

Data matter because they are used by employers to make management decisions; by commissioners to determine how much money to pay for services; and by the government for its various schemes, such as NHS Choices. This is happening now, and in the future data will be increasingly used to assess the quality of services provided by hospitals, departments, and most likely eventually individual surgeons.

As clinicians we need to be intricately involved in the process. This stresses the vital importance of the engagement of clinicians, the Royal Colleges and specialist associations in influencing the wider processes of data capture now, to ensure that the data are of good quality and accurate, so that clinicians can be judged appropriately. Good-quality data also have a wealth of other practical benefits.

In the United Kingdom annual appraisal is a requirement of medical registration, and revalidation commences this year. Surgeons will be expected to produce evidence of volume, case-mix and outcomes. Good-quality data can not only be used to support the appraisal process but should also limit the preparatory time. In an appropriately designed system, data on a surgeon’s workload, complications, NJR data and all assessments should all be readily available. Data can be gathered to assist in management discussions, such as departmental workload and resource planning, and for the purposes of audit and research. Most importantly, good data will enable clinicians and departments to improve their practice and the care they give.

It is of course recognised that many surgeons have for many years kept their own data on spreadsheets or local databases; however, inconsistencies of coding, lack of connectivity to other databases, and increasingly stringent data protection laws might make such local databases more difficult to justify in the future.

Most hospitals are exploring the introduction of electronic patient record systems, and orthopaedic departments should insist that they be involved in the process, and that systems are in place to ensure that the data are accurate and complete and that every patient seen, in both inpatient and outpatient settings, has a diagnostic and treatment code ascribed and verified by the treating clinician. Departments will have to decide whether the process can be added to their workload or whether extra clerical support is required. Consultants also have a duty to train juniors in the importance of good-quality data.
There is no doubt that the information revolution has already happened and, as with any revolution, change can be daunting while also providing great opportunities for improvement. If the Government and the Department of Health are to demonstrate their commitment to quality, they need to engage and work closely with the profession to ensure that data are analysed and reported appropriately to protect the interests of patients and the care they receive.

Ultimately, it is our responsibility to develop world-class services with clear and transparent outcomes that will lead the way in determining the care that we offer in the future.

Although none of the authors has received or will receive benefits for personal or professional use from a commercial party related directly or indirectly to the subject of this article, benefits have been or will be received but will be directed solely to a research fund, foundation, educational institution, or other non-profit organization with which one or more of the authors are associated.

References