APPENDIX 2

	A Author	B Title	C Year	D Name of registry/type of paper	E Type of surgery	F Collaborations	G Registry leadership and management	H Objective(s)	I Registry development and design	J Funding	K Rationale behind dataset	L Dataset	M Data processing	N Strategies to increase data completion	O Data completeness	P Data reporting	Q Patient involvement	R Difficulties encountered/challenges	S Benefits of registries	T Measures of a successful registry	U Legal factors, ethics and data access
1																					
2	Gabr A. O'Leary S. Spalding T. Bollen S. Haddad F.	The UK National Ligament Registry Report 2015	2015	UK National Ligament Registry (NLR)	Anterior cruciate ligament reconstruction (ACLR)	NS	Steering committee group comprising of surgeons - no initial involvement of government	To collect relevant demographic data, identify current or emergent trends in practice, identify failing techniques/devices at the earliest opportunity, provide functional outcome data and complication rates, improve the standard of care	Web based platform	Involving physical therapists with enrich dataset. Industry (8 companies, priming grant from British Association for Knee Surgery BASK) - Industry will be provided with information on the performance of their products. They will not be able to access the raw data	Need to have a balance between level of ideal data and what surgeons and patients can easily submit. The data set allows comparison and communication with existing registries as well as allowing potential 'generic health benefit' comparisons with other non-orthopedic procedures	Demographics, cause of injury, time from injury to surgery; graft data (type of graft, diameter), BMI, surgical technique; outcome data relating to ACLR. knee injury and osteoarthritis outcome score, subjective International Knee Documentation Committee, Euroqol (EQ5D) and the Tegner activity score, in which centre procedure performed.	NS	User-friendly wed based platform - easily accessible via computer or tablet, simplifying the process for clinicans and patients; Has a registry 'route' - requiring small contributions from patiens and surgeons at different stages; Has automatic prompts for patients to fill in their information at scheduled times of treatment and rehabilitation, taking the hassle and stress out of clinical data collection for clinicians; Readymade tool for use in governance and revalidation	17,800 completed forms. 2854 ACLR procedures registered between Dec 2012 and Feb 2015. Estimated that there are 30,000 patients a year in the UK undegoing ACLR	NS	Patients can insert data via apps	NS	NS	NS	May be useful to introduce mobile apps for surgeons use to enter data
3	Hing C.B. Stiehl J.B.	Editorial	2015	Commentary	NS	NS	NS	NS	NS	NS	NS	NS	Registries rely on accurate robust data entry and and correct support	NS	NS	NS	NS	NS	NS	NS	NS
4	Briggs V. Pitcher D. Braddon F. Fogarty D. Wilkie M.	UK renal registry 15th annual report: Chapter 8 UK multisite peritoneal dialysis access catheter audit for first PD catheters 2011	2011	UK renal registry Multisite peritoneal dialysis access catheter audit	Peritoneal dialysis access.	NS	NS	Data acquisition relating to peritoneal dialysis functionality and access	NS	Health quality improvement partnership (HQUIP)	Data fields were refined from existing renal registry tables. Data fields were adjusted based on meetings with a multisite audit group including patient representation.	Demographic data, age at first dialysis of each centre, size of centre, referral time/interval, underlying disease, catheter insertion technique, referral time, commencement date of dialysis, deprevation quintiles, catheter survival at 3 months, length of time known to nephrology service, date catheter used, date of catheter failure, BMI, date seen by renal physician, surgical referral, peritoneal dialysis catheter outcomes, complications	Excel spreadsheets circulated by the UK renal registry.	NS	43/65 centres contacted submitted data. Data completeness by center ranged from 0% to 100% for almost all data fields that were collected. Data RE: underlying renal disease not available for 13% of patients. Data not avilable from some renal networks RE referal time; "considerable missing data" RE surgical referral. Missing data RE insertion technique in 37 patients. Missing data in 209/916 patients RE whether or not they were diabetic	NS	Patient involved in refining data fields	NS	NS	NS	NS

5	Divecha H.M. Siddique I. Breakwell L.M. Millner P.A.	Complications in spinal deformity surgery in the united kingdom. Five year results of the annual british scoliosis society national audit of morbidity & mortality	2014	British Scoliosis Society	Spinal defority surgeries	NS	NS	Provide an overview of corrective spinal deformity surgery including case volume and complication rates	NS	NS	NS	Aetiological and outcome data. Number of surgeries performed, demographics, aetiology (idiopathic vs non-idiopathic), complications (mortality, deep infections, neurological deficit), in which centre procedure performed	Individual units were approached on an annual basis and asked to submit data (voluntarily). Data was submitted electronically	It may be necessary to make it mandatory to submit morbidity and mortality data to ensure accurate, representative and nationwide data collection.	82% of centres (51 centres). The number of contributing units and cases increased yearly throughout the study period	NS	NS	Relied on voluntary data submission by individual centres leading to potential reporting bias where complication rates could be underestimated.	Help when consenting patients in terms of complication rates. Help provide a benchmark for units in the UK to compare their complication rates against national averages.	NS	NS
6	Briggs V. Pitcher D. Shaw C. Fluck R. Wilkie M.	UK renal registry 16th annual report: Chapter 14 2012 multisite dialysis access audit in England, Northern Ireland and Wales and 2011 PD one year follow-up: National and centre-specific analyses	2012	UK renal registry Multisite dialysis access audit	Vascular and peritoneal dialysis access.	NS	NS	Examine practice patterns of dialysis access and highlight variations in practice between renal centres	NS	HQUIP	NS	Patient demographics, details of access failure, type of access, first access type used, insertion technique, referral time, type of renal disease, whether pt had surgical assessment, in which centre access was obtained, complications	Excel spreadsheets circulated by the UK renal registry.	NS	51/62 centres	NS	NS	Data collection was not optimal with significant amounts of missing information across range of data fields. There were ambiguities in data fields which need to be refined to simplify collection and improve accuracy	NS	NS	NS

Kolias A.G. Bulters D.O. Cowie C.J. Wilson M.H. Afshari F.T. Helmy A. Broughton E. Joannides A.J. Zebian B. Harrisson S.E. Hill C.S. Ahmed A.I. Barone D.G. Thakur B. McMahon C.J. Adlam D.M. Bentley R.P. Tolias C.M. Mitchell P.M. Whitfield P.C. Critchley G.R. Belli A. Brennan P.M. Hutchinson P.J.	Proposal for establishment of the UK cranial reconstruction registry (UKCRR)	2014	UK Cranial reconstruction registry (UKCRR). Proposal for the establishment of a UK cranial reconstruction registry	Cranioplasty. Reconstruction of the skull vault with autologous bone, titanium or synthetic material.	British Neurotrauma Group, the British Neurosurgical Trainee Research Collaborative (BNTRC), the UK Neurosurgical Research Network, Society of British Neurological Surgeons	Each participating unit will appoint a consultant and a trainee responsible for co-ordinating the UKCRR at a local level. The UKCRR Steering Committee will have the overall responsibility for oversight of the registry. Steering Committee meetings to assess progress will take place at 6 and 12 months after the national rollout. A Steering Committee, which will include stakeholders will be responsible for overseeing the strategic direction and running of the UKCRR	To monitor practice patterns, complication rates and establish benchmarks for future studies. To provide information on variations in practice and outcomes between different units. To generate hypotheses for furture research studies. Ultimate aim is to improve outcomes for patients. Specific objectives of the UKCRR are to: Monitor the demography, contemporary practice patterns, long-term clinical outcome and complication rates of cranioplasties across the UK. 2) Collect PROMs with a special focus on functional outcome, quality of life and satisfaction with cosmesis. 3) Provide aggregate data of implant usage and lifespan (implant survival) for long-term surveillance to manufacturers (commercial and in-house), clinicians, healthcare planners, regulatory authorities and other stakeholders	The UKCRR will be developed under the auspices of the British Neurotrauma Group (a special interest group of the Society of British Neurological Surgeons), the British Neurosurgical Trainee Research Collaborative (BNTRC) and the UK Neurosurgical Research Network. The registry will operate under the umbrella of the National Neurosurgical Audit Programme of the Society of British Neurological Surgeons. The feasibility of prospective data collection will be piloted in a number of selected units to refine the dataset on user experience and feedback. The pilot phase is expected to last 2–3 months. The principles of the UKCRR were discussed and agreed during past meetings of the British Neurotrauma Group and the launch meeting of the BNTRC	Cost of development and maintenance to be met by participating hospitals with supplier contributions using the UK shunt registry funding model. Industry will make some funding contribution	Dataset agreed during previous meetings with stakeholders and overseen by steering comittee. Well established and validated patient reported questionnaires will be used. For QOL, they propose to use the EQ-5D - a validated, non-disease-specific instrument which measures health-related quality of life and health status - it's use is recommended by the National Institute of Neurological Disorders. A PROM focussing on satisfaction with cosmesis post-cranioplasty does not currently exist. Authors intend to develop and validate an appropriate instrument in partnership with patients and patient support groups	Demographics, indication for craniectomy, site of craniectomy, type of skin incision, material used for duroplasty, type of material laid over the brain, time interval between craniectomy and cranioplasty, comorbidities, ASA class, neurological status, PROMs (functional outcome, quality of life, satisfaction with cosmesis). Operative data including: number of surgeons, grade of most senior surgeon, morning or afternoon operating list, size of cranial defect, site of cranioplasty, type of cranioplasty (including material, design and manufacturing), simultaneous insertion of CSF shunt (if applicable), surgical time, antibiotic prophylaxis, conventional or laminar flow ventilation theatre, wound infiltration with local anaesthetic, type of antiseptic used for skin preparation, distance of brain surface from inner table of skull, part of implant placed under temporalis (if applicable), method used to secure implant, insertion of wound drain (suction or passive) and method for closing wound. Outcome measures: Re-operation due to a cranioplasty-related issue, surgical site infection, re-admission due to a cranioplasty-related issue, unplanned post-operative escalation of care, morbidity, length of stay, destination at discharge, mortality, neurological status, PROMs (functional outcome, quality of life, satisfaction with cosmesis) during routine follow-up	The elective waiting list and/or other clinical management systems will be used for the identification of eligible patients. Data will be submitted by members of the local clinical team to the Outcome Registry Intervention and Operation Network (ORION) secure online platform, which already hosts the national vestibular schwannoma registry, national paediatric epilepsy surgery database and the UK chronic subdural haematoma audit. UKCRR Steering Committee in partnership with the ORION will be responsible for central processing and validation of anonymised data	NS	Not active yet	Annual reports including: a summary of cranioplasties (material, time interval after craniectomy, patient characteristics), outcomes post cranioplasty, description of key outcome indicators (i.e. risk-adjusted re-operation and surgical site infection) at unit level, description of data completeness at unit level	NS	NS	NS	NS	The ORION platform complies with the Department of Health Information Governance policies and standards for secure processing of patient healthcare data as set out in the Information Governance Toolkit of the Health and Social Care Information Centre. Each participating unit will be the data controller for its own submitted data

Hickey G.L. Grant S.W. Cosgriff R. Dimarakis I. Pagano D. Kappetein A.P. Bridgewater B.	Clinical registries: Governance, management, analysis and applications	2013	Review on establishing and managing registries. Uses many examples from National Adult Cardiac Surgery Audit (NACSA) registry	General review on registries but mainly focuses on cardiac registry	Stakeholders in NACSA registry, DoH commissioners, HQIP: The Healthcare Quality Improvement Partnership, SCTS (Society for Cardiothoracic Surgery in GB and Ireland), NICOR: National Institute for Cardiovascular Outcomes Research, NIGB: National Information Governance Board, Cardiac Surgery Centres, Surgeons, Database managers, Academic groups, Commercial groups	NACSA managed by National Institute of Cardiovascular Outcomes Research (NICOR). For NACSA database, most centres in the UK employ a local database manager who has responsibility for working with the surgeons to ensure that data collection is complete and robust. Database managers monitor data completeness rates and effective data management is a vital aspect of any large clinical registry. For registries to be effective, dedicated clinical input alongside high-level analytical and data management expertise is required	This review covers the fundamentals of establishing and maintaining clinical registries	NS	Registries require considerable resources, infrastructure and funding to survive long term. Funding can come from: government budgets; professional societies; local health-care commissioners. The value of the data can be exploited as a source of revenue. The Society of Thoracic Surgeons (STS) have identified two revenue sources for their national database: (i) non-funded major or minor data requests and (ii) regional activities. The first source allows for researchers to access information from the database. The second would allow for regional governments to access high-quality reports in order to steer health-care policy.	Fewer participants and small datasets increase participation rates and data completeness. However if too small, not useful. A registry that can easily evolve to capture new data sources or fields is likely to be expensive and complicated, but one that is inflexible can become outdated. The first agreed dataset for the NACSA registry was in 1996 and revised in 2003 and 2010. Each revision required comprehensive communications with all contributors and external software developers.	The NACSA dataset has 168 data fields. Half the fields are 'branched', meaning that they are only relevant for specific procedures. Fields are classified into patient identifiers, patient characteristics, medical history, preoperative measurements, intraoperative fields and postoperative fields. Cardiac surgical procedures are categorized into four major groups: coronary artery bypass graft (CABG), valve, major aortic and other cardiothoracic procedures. Indication of a procedure within one of these groups unlocks further branched fields. For example, indicating a patient had a CABG procedure would unlock fields to allow completion of the number of grafts.	For NACSA: Data are collected through local specialised database systems developed either commercially or locally. The data remain in the individual centres for internal validation and local auditing. Data are then uploaded to central servers housed at NICOR. A sophisticated registry-import software tool flaggs data issues. Data are then merged into a single file structure and encrypted. Data then undergo central data cleaning and external validation. It is very important to be able to clean the data. Simply removing records or fields that do not fully meet standards of accuracy and coherency will lead to an increase in bias. Data cleaning is the process of detecting and resolving data problems to improve data quality. Appropriate resources must be allocated to this process, which will usually require the attention of experienced clinicians and database managers. Data validation is important to ensure that the data are accurate for reporting. Following local and external validation, summaries of centre- and surgeon-specific data are returned to individual centres for validation. Following this, data can be released to the public domain.	Achieving and maintaining high participation rates rely heavily on the perceived value of the outputs generated. Keep the registry simple - as the number of records, data fields and complexity of the registry increases, the quality of the data decreases. Have comprehensive 'user guides' for contributors, technical and clinical helpdesks, training, feedback mechanisms and communication plans. Problems most commonly occur at the data input stage. Data inputted using handwritten data-forms are more likely to contain inaccurate information than software systems that capture the required dataset. Human error can also lead to data extractions for researchers being unknowingly corrupted. For example variables that list multiple options separated by a marker might be arbitrarily truncated, meaning that not all data are transmitted	The NACSA database contains over 450,000 records	Publishing mortality results by named centre/surgeon might encourage risk-averse clinical decision-making. However evidence is inconclusive.	NS	Examples of errors from NACSA include patients who have their heights recorded as negative values (e.g. −160cm), procedures on five valves, deceased patients being discharged home and aortic root replacements being performed on the abdominal aorta	Improves quality of patient care, underpins research, improves cost-effectiveness, provides information for regulatory process. Other benefits include improvements in informed patient decision making, improvements in treatment and advances in health-care research and governance. Since the NACSA registry was introduced, risk-adjusted in-hospital mortality in the UK has fallen by >50% despite more elderly and high-risk patients having surgery each year. It is increasingly accepted that the collection and feedback of data and publishing them openly, is an effective way of driving quality improvement. Registries can be used for audit purposes, surgical epidemiology, clinical hypothetis testing, risk-prediction models (eg in cardiac surgery used to estimate short term mortality post surgery), epidemiological research, health services research (including variations in patient access to care), and identification of health care inequalities. Clinical registries are considered the gold standard of observational data. There have been an increasing number of devices implanted into patients. Registries would allow the earlier detection of unacceptable failure rates eg PIP	The success of a clinical registry project can be measured on the database completeness, accessibility of information and proven usefulness	Essential for the registry to function within its legal framework. Failure to do so can be a terminal event for any registry with potential criminal or political repercussions. There have been conflicting legal views on the interpretation of UK laws for practice in health-care research which has disrupted a number of registry projects due to lack of legal clarification. There should be ethical use of data and appropriate intellectual property rights. Data privacy should be maintained and data should be protected. Patients' personal data should be accurately collected and stored securely and not shared without appropriate permissions. It is important that any release of data (including to third parties responsible for analysis or publication) is done under a defined data-sharing agreement, whereby the security, planned uses, control and fate of the data are clearly defined

9	De Steur W.O. Henneman D. Allum W.H. Dikken J.L. Van Sandick J.W. Reynolds J. Mariette C. Jensen L. Johansson J. Kolodziejczyk P. Hardwick R.H. Van De Velde C.J.H.	Common data items in seven European oesophagogastric cancer surgery registries: Towards a European Upper GI cancer audit (EURECCA Upper GI)	2014	European Registration of Cancer Care (EURECCA) Upper GI Project	Upper GI Surgery	European Society for Surgical Oncology (ESSO) and the European Network of Excellence on gastric and oesophagogastric junction cancer (EUNE). Several European national and regional oesophagogastric cancer registries, countries involved: Denmark, France, Ireland, the Netherlands, Poland, Sweden, United Kingdom	NS	To compare the datasets used by the seven participating European oesophagogastric cancer registries and audits and to identify a list of common items. This core dataset can be used for future collaboration in the EURECCA Upper GI project	NS	NS	This study looked at data item lists from all seven participating Upper GI cancer registries, and then developed a core dataset based on shared items	By comparing the datasets of the 7 participating registries, 46 items were identified as shared items for a core dataset. The items were categorized into the following subgroups: patient administrative/medical condition, staging/diagnostics, neoadjuvant treatment, surgery, postoperative course/complications, pathology, adjuvant treatment and survival/follow up	Validity of self-reported data should be checked	The EURECCA Upper GI project provides participating teams with the opportunity to benchmark their performance on a European level	NS	NS	NS	Not all European countries could participate because of limited availability of national/regional registries and audits. Definitions for postoperative complications differ among countries. In order to compare the data from the different registries, agreement has to be obtained concerning the definition of all complications used in the registries	Using the European Upper GI core dataset, differences in treatment patterns can be identifed and linked to outcome measures such as morbidity, mortality, and surgical margins. The dataset offers enough patient data to perform statistical corrections for patient- and tumour factors, necessary for a fair comparison between different treatment strategies. Collective data may answer questions concerning the optimal treatment for elderly patients, which are often excluded from randomized trials, but in daily practice form a significant proportion of the patient population with oesophagogastric cancer	NS	NS
10	Sessler D.I.	Big Data - And its contributions to peri-operative medicine	2014	Commentary on benefits and uses of registry data	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	Increase reliabily of data. With sufficient patients it is possible to study rare diseases, accurately evaluate 'hard' outcomes such as mortality, and generate appropriate comparison groups for case-control and retrospective cohort studies. Registry analyses can be conducted quickly and at modest cost. Registry data can be used for: 1) case-control and retrospective cohort studies; 2) health services research; 3) quality assessment; and 4) modelling for and conduct of prospective studies. Registry data will help physicians, epidemiologists and health policy experts to make data-driven decisions that will ultimately	NS	NS

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11	Breakwell L.M.	Understanding the need for spinal registries: Lee Breakwell reviews the importance of registries in spinal research and explains why the British Association of Spinal Surgeons (BASS) has decided to set up its own registry	2013	Commentary on why and how the BASS decided set up the British Spine Registry	Spine	Association of British Healthcare Industries (ABHI) has enabled listing of the majority of the available spinal implants. This enables access to data on usage and helps identify national outcomes	NS	To enable assessments of certain procedure types, and their outcome. To create a secure, comprehensive database, to allow individual surgeons and their teams to collect prospective data in a convenient and timely manner	A subcommittee was formed, led by a consultant spinal surgeon, to define the dataset and to create a tender process. Bluespier International was the successful company, and has worked with the BASS registry committee to design and launch the BSR on the Amplitude platform.	NS	A subcommittee led by a consultant Spinal Surgeon defined the dataset	Demographics, indication, details of the presenting clinical symptoms, resulting operative data, type of spinal implants, PROMs data	NS	A web-based solution was developed, ensuring that all users could access the BSR wherever, and whenever they wished	Currently there are over 200 registered surgeons, and over 3,000 patients enrolled in the registry	NS	Use of a patient portal for direct data input is recommended	NS	Disciplined data collection can result in improved patient care through identifying trends and early problems. Registries help the drive towards value based health care - increase quality whilst reducing costs. The societies will be for the first time able to create real-time accurate population data on spinal surgery in the UK.	NS	To addess data security - the BSR has been registered with the UK Information Commissioners Office, the Healthcare Quality Improvement Partnership, and the Record of Central Returns. In addition, NHS IT experts reviewed the security policies, and data storage technology
12	Hickey G.L. Cosgriff R. Grant S.W. Cooper G. Deanfield J. Roxburgh J. Bridgewater B.	A technical review of the United Kingdom National Adult Cardiac Surgery Governance Analysis 2008-11	2014	United Kingdom National Adult Cardiac Surgery Governance Analysis 2008–11	Cardiac surgery	Society for Cardiothoracic Surgery in Great Britain and Ireland who contribute data to the SCTS database. National Institute for Cardiovascular Outcomes Research, UCL London. National Adult Cardiac Surgery Audit	NS	To give a technical review of the registry	NS	HQUIP	NS	Each record contains a hospital identifier code and a consultant GMC number.	Data entered locally by surgeons are validated by database managers prior to upload via a web-portal to NICOR. At this stage, further validation is performed according to logical rules. The data are then forwarded to an academic healthcare informatics department for data cleaning. Cleaning involves removing duplicate records, recoding transcriptional discrepancies and resolving clinical and temporal conflicts. The data cleaning is performed by the analyst responsible for the governance analysis in collaboration with surgeons and the audit manager. All cleaning is made reproducible by programming a series of scripts, which are updated following each new data extract. At this stage, and prior to analysis, data for the last 3 years are returned to each contributing hospital for local validation, and units update their records in the central registry	NS	Most missing data are resolved during the validation stages of the data transfer. SCTS has a policy for the handling of missing data. First, missing and conflicting data for in-hospital mortality status are backfilled and validated via record linkage to the Office for National Statistics (ONS) census database, which records details of all deaths in England and Wales. After all reasonable attempts to backfill these data, any remaining missing discharge status data are mapped to in-hospital death. For the final analysis dataset after backfilling discharge status data, in Scotland there were 0 (0.00% of Scottish records) missing discharge statuses; in Wales and Northern Ireland, there were 3 missing discharge statuses each (0.06 and	Data is reported on both the base hospital and the responsible consultant surgeon. Risk-adjusted in-hospital mortality, length of stay, postoperative complications, morbidity	NS	NS	Improve overall service quality, and enable pts to make a choice between providers. Increase public trust, identify underperforming units	NS	NS

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13	Mangera A. Parys B.	BAUS Section of Endourology national Ureteroscopy audit: Setting the standards for revalidation	2013	Audit of UK Uteroscopy	Ureteroscopy	British Association of Urological Surgeons	NS	Aim is for this audit to develop into a registry	NS	Nil funding	A consensus proforma was produced by the BAUS Section of Endourology to capture all necessary data. The proforma was created using the percutaneous nephrolithotomy registry as a basis. It was initially approved and piloted by the BAUS Section of Endourology Data and Audit committee. Thereafter it was approved by the BAUS Audit committee.	Patient demographics, procedure side, elective/emergency, grade of surgeon, number and site of stone(s), size of stone, pre-op investigations, whether stent was used pre-operatively, use of prophylactic antibiotics, supervised training operation, procedure (rigid/flexible ureteroscope), difficult access, accessory procedures, percentage of procedures abandoned, total stone clearance rate, complications, length of stay, post operative imaging	NS	A national prospective audit link was sent to all consultant members of the BAUS Section of Endourology. Members were encouraged to complete the standardised proforma for all URS undertaken for stone management during a two week period (23 April 2012–6 May 2012). To develop this audit into a registry. Compulsory Surgeon participation, which may occur with revalidation, may provide the only means of accurate data capture	143 procedures were recorded. 26% of cases performed in England were recorded	NS	NS	Follow-up period was short, and long-term complications will be missed. There was no precise definition for day-case surgery. Surgeons are already under increased pressure to record and document all surgical activity and a registry will inevitable increase this burden. Time constraints may compromise accurate and timely data recording and lead to apathy in some surgeons, limiting participation.	NS	NS	NS
14	Franklin P.D. Harrold L. Ayers D.C.	Incorporating patient-reported outcomes in total joint arthroplasty registries: Challenges and opportunities	2013	Total Joint Arthoplasty	Total Joint Arthoplasty	NS	NS	This paper reviews the use of Patient reported outcomes (PROs) by worldwide TJA registries, the challenges of integrating PRO's in national implant registries and lessons from registries that have used PROs	NS	Whether government-funded or supported by specialist bodies, manufacturers , or research agencies, the costs of registry data collection must be justified by the value of the knowledge gained from the analyses.	Omitting patient-reported outcomes precludes surgeons from fully understanding the factors that contribute to pain relief, restoration of function, and patient satisfaction. PROs are increasingly used in the allocation of healthcare resources and comparative effectiveness research. PRO data must be valuable to multiple stakeholders to justify the incremental costs of their collection. Important to choose suitable PROs and develop innovative methods to collect data. To improve long-term data completion, some registries collect PRO's directly from patients at regular intervals after TJA. It is better not to rely on collecting data when patients retun to clinic rather it is better to collect data directly fom patients (direct-to-patient models). There was a lack of consensus over	Implant longevity, revision rates, patient demographics, BMI, co-morbidities, PROs related to pain relief and functional gains	NS	Registry procedures should be simple to increase participation. Returning registry data to the surgeon encourages ongoing commitment to complete data collection	NS	NS	Direct entering of PRO data by patients via web-based software and mobile phones will help improve follow-up data. To increase patient participation in their own data collection, it is important to engage the patient during the consent process, have a registry coordinator to follow up the patient to encourage participation, make it easy for patients to enter PRO data electronically, and have multiple languages available. Beneficial to consent patients to be enrolled in PRO capture at the time surgery is scheduled	This review found that most data is collected at the time the patient undergoes the procedure, but postoperative follow up data is often lacking - due to different clinician/hospital.	Enable monitoring of postdischarge outcomes and identify patient who may be at risk for implant failure. PRO's also help guide best practices and help regulate implants providing important information to manufacturers. Such data informs surgeons practice and enables self-audit	The International Society of Arthroplasty Registries defines a full member registry as one that captures more than 90% of all cases and clinically validates the data	NS

										which PRO to choose - generic measures or condition specific, pre and post op PROs or only pre/post. It can be time consuming to enter PRO data and can be difficult to engage patients to enter their own PRO data.									
Bulusu V.R. Fullarton J. Leahy M. Morgan C. Rasheed A. Taniere P. Toh S. Verrill M. White J. Judson I.	Rationale and design of a UK database for a rare cancer type: The GEM Registry for gastrointestinal stromal tumours	2013	GIST Epidemiology and Management (GEM) Registry	GIST tumours	NS	The registry is regulated by the UK GEM Registry Steering Committee, comprised of recognised experts in GIST.	Aim of paper: To describe the rationale and study design of the GIST Epidemiology and Management (GEM) Registry. Aim of registry: to further characterise patients with GISTs and to provide comprehensive data to improve understanding of the incidence, treatment and outcomes of GISTs in the UK	Web-based system. The GEM database has been designed around a Microsoft Access (MSACCESS) core using a SQL interface from specifically designed Active Server (asp) web pages. There are two main data input pages, for clinical and pathological (extended) data, together with facilities for reviewing historical records for each patient and generating real-time reports on the current database content. Piloting the registry was useful. It allowed GIST clinicians using the registry to test the software and identify any areas for improvement - suggested modifications were agreed by the Steering Committee before implementation on the website	Development of the UK GEM Registry and ongoing training was supported by an unrestricted educational grant from Novartis Pharmaceuticals UK limited	NS	Demographics, date of diagnosis, tumour characteristics, referral source, mode of presentation, biopsy details and date of procedure, rupture (yes/no), risk assessment, tumour type, details of resection, adjuvant treatment, details of metastases, relapse date, participation in clinical trial (yes/no), date and case of death, consent received, loss to follow up recorded. For centres willing an extended data set was available	Periodic on-site quality assurance checks are maintained, together with continuous statistical comparisons of local data between centres to warrant data consistency.	The interface pages provide real-time assistance with data input, by providing reminders for mandatory fields, acceptable ranges for numeric fields, calendar support for dates and drop-down boxes for most text input. Data clerks, nurses and clinicians at each participating centre attended training sessions to ensure data accuracy. Every unit had training on the use of the registry tool. A user guide was available and e-mail and telephone support was provided. Ongoing training and support for newly recruited centres, drop-down boxes, calendars and numeric limits in the web-based software interface can reduce the likelihood of human error	NS	NS	NS	NS	The registry data will provide important insights into the incidence, prevalence, recurrence, survival and mortality rates of GISTs, as well as treatment practices throughout the UK, thereby enabling therapeutic intervention to be evaluated and ultimately optimised. It will also help review prognosis and assess long term treatment benefits and improve quality of care delivery. This information will help inform clinical practice and guide the development of clinical trials	NS	The Registry will be implemented and reported in accordance with applicable local regulations and with the ethical principles laid down in the Declaration of Helsinki. Ethical approval was granted centrally for the registry via the National Research Ethic Service. Eligible patients will only be included in the study after providing written, informed consent. All data will be anonymous. Data stored on either local hospital server or at server maintained by commercial host. Periodically, locally stored information is uploaded to the central UK GIST Registry (National Data set) held on the host server. User access to the system is password protected and has multiple levels of privilege for data editing, record deletion, transmission to the central server & creation of new user accounts. Clinicians are able to access the system from anywhere by logging in via the hospital intranet. The Steering Committee reviews the requests for access to the registry. Each request is carefully reviewed on a case by case basis and appropriate access granted for ethically approved research projects. Access to the system is limited to individuals having access

16	Head S.J. Howell N.J. Osnabrugge R.L.J. Bridgewater B. Keogh B.E. Kinsman R. Walton P. Gummert J.F. Pagano D. Kappetein A.P.	The European association for cardio-thoracic surgery (EACTS)database: An introduction	2013	The European Association for Cardio-Thoracic Surgery (EACTS) Database	Adult cardiac surgery	European centres	Dendrite Clinical Systems Ltd. (Oxfordshire, UK) would take care of data management and analysis. The Database Committee, with oversight from the EACTS council, was installed to manage the database	This is a paper that provides an overview of the European Association for Cardio-Thoracic Surgery (EACTS) Database (UK is included). The registry aims to collect comprehensive data on the practice of European adult cardiac surgery, and disseminate information that it is easily accessible and understandable to the surgical community, patients and the general public. This will provide invaluable assistance to surgical teams when they are in negotiation with healthcare providers, enabling them to acquire the appropriate resources for their patients and allowing them to develop and hone surgical practice so as to ensure the continued improvement in outcomes for patients	EACTS planned to use the American STS dataset with several adaptations to suit the European population- this would be less time consuming and simpler for the EACTS team	NS	EACTS would use the American Society of Thoracic Surgeons dataset with adaptations to suit European demographics.	Procedure performed, patient demographics, postoperative length of stay, all-cause mortality	Data import would be primarily organized through national registries the data would already have been cleaned and processed. Dendrite Clinical Systems Ltd hosted the database and took care of data management and analysis. Various logic checks and validation processes were applied by the Dendrite team to ensure that major problems with data or issues with formatting were identified. In some cases, extensive dialogue was required between Dendrite and the contributors to investigate potential problems and take the appropriate remedial action so that data could then be resubmitted in the correct format	The chairman of the EACTS committee sent an invitation to the chairmen of 23 national registries to ask them to participate. Invitation letters are still sent out every year to encourage past contributors to send their most recent data and to persuade more hospitals and countries to begin contributing. Using a web-based data submission tool with concomitant data validation checks and early recognition of errant or missing data could help to drive improvements in data quality and so increase the overall utility of the database. Complete data would provide accurate trend analysis and allow for proper risk-adjusted mortality analysis. One key requirement is that all participating centres standardize on one definition for mortality	For the last database report in 2009, data were available from 366 hospitals located in 29 countries. Data of 1 074 618 patients were included in the database	Publications, presentations, annual reports.	NS	Data import would be primarily organized through national registries - downside of this approach, could be that some countries might have a more advanced national registry than others, and the more established datasets might be significantly divergent from the requested dataset. In the current EACTS database, it is not appropriate to compare the mortality rates between countries, because adjustment for the types and complexity of patients and procedures cannot be performed adequately. The submitted data often did not represent the complete number of cases of a country, and it could not be determined what the percentage of submitted data was. Therefore, regional trends should be interpreted with caution. The percentage of missing data in the submissions from some countries is another area for potential improvement. A key area of improvement would be that all participating centres standardise on one definition for mortality	Provides good overview of cardiovascular surgical practice in Europe. Reports the safety and efficacy of procedures, assess the appropriateness of usage, benchmark outcomes, evaluate trends and variability, appraise governmental interventions and estimate healthcare expenditure	NS	All data are anonymised
17	Patrick H. Sims A. Burn J. Bousfield D. Colechin E. Reay C. Alderson N. Goode S. Cunningham D. Campbell B.	Monitoring the use and outcomes of new devices and procedures: How does coding affect what Hospital Episode Statistics contribute? Lessons from 12 emerging procedures 2006-10	2013	Hospital Episode Statitics (HES) data	Twelve interventional procedures were selected: 11 from published NICE Interventional Procedure Guidance (IPG) and one without NICE guidance (iliac artery stenting) but suggested by a professional society	NS	NS	The aims of this study were to assess the availability and accuracy of routinely available HES data as a tool to monitor the introduction of new interventional procedures into practice and to investigate whether the coverage of the data for individual procedures is affected by the complexity and specificity of their OPCS-4 codes	NS	NS	HES uses the Office of Population Censuses and Survey (OPCS-4) Classification of Surgical Operations which is supported, maintained and developed by the NHS Classification Service (NCS)	Procedure type, number of procedures carried out per year, number of hospitals in which they were likely to be done	HES data were extracted for all 12 procedures, for 4 financial years (2006–10) based on year of finished consultant episode and were imported into a local, securely held, Structured Query Language database for analysis. National registers aim to achieve comprehensive coverage but they do not provide a 'gold standard data set' and therefore the sensitivity of data was analysed (i) using register data as the reference data set and then (ii) using HES data as the reference data set. As a check of data quality, prior to undertaking any detailed analysis, the quantity of relevant episodes of care in the HES extract was	Where they couldn't identify any national or local data set, relevant manufacturers were contacted to ask for sales data. Manufacturers were contacted by telephone, letters or e-mails and asked to provide UK sales figures broken down by financial year (2006–10) and by hospital	NS	NS	NS	Reason for lack of registry data may include the lack of resources to enable the data collection and submission, and scepticism about the quality of data	Can provide evidence on efficacy, safety and cost-effectivness. Enables ongoing montioring of new interventions. Enables NICE evaluation. Facilitated self audit and demonstrate continuing professional competency. Helps inform Health Service Commissioning decisions (with the ultimate aim of evaluating how resources used relate to services delivered and health improvements achieved)	NS	NS

checked at an aggregate level against data available from the HESonline website. Our findings demonstrate that for procedures with simple specific codes (i.e. not requiring complex combinations of codes to describe the procedure), HES can accurately identify hospitals using new procedures and the numbers of those procedures undertaken. In contrast, HES data show poor specificity for procedures requiring complex combinations of OPCS coding. HES may help to identify hospitals that have not registered cases on national databases. HES data may be useful to improve the quality of national registers. For example, this has been successfully achieved in the National Bowel Cancer Audit Project by the Association of Coloproctology of Great Britain and Ireland, which used HES to check the coverage of the Audit, and the UK National Joint Register which demonstrated important variations in hip and knee replacement revision rates through linkage of its data to HES

Welbourn R. Small P. Dexter S. Hewin D. Kinsman R. Reddy M. Sedman P. Somers S. Walton P.	The UK national bariatric surgery registry: The second report	2013	UK National Bariatric Surgery Registry	Bariatric surgery: gastric bypass, gastric banding and sleeve gastrectomy	British Obesity and Metabolic Surgery Society (BOMSS), Association of laparoscopic surgeons, Association of Upper gastrointestinal surgeons and Dendrite.	Registry management by Dendrite clinical systems. Day to day administration by BOMSS. Oversight of the database design controlled by NBSR Database committee.	To provide a nationwide analysis of outcomes from bariatric and metabolic surgery in the UK an Ireland	Bespoke registry built by Dendrite. Hosted on a secure Dendrite server within the NHSNet N3 network. This N3 network has a fast link from any NHS computer that has NHS intranet access. The server also has a network card which gives secure access from outside the NHSnet, so that data can be entered from any private hospital.	No Public funding. Anticipates receiving funding from HQUIP.	There were 22 fields in the database that were absolutely required for meaningful data collection. The follow up data entry section allows for data capture of an unlimited amount of longitudinal data and the status of each comorbidity in detail so that the long term benefits of weight loss surgery can be assessed	Demographics, mortality, how each pt was funded, length of stay, complications, BMI pre-op, ASA, functional status, operating surgeon, type of operation, operative approach, co-morbidities, functional impairment, additional procedures, mortality data at the level of the individual surgeon. weight loss post op, change in co-morbidities post op, discharge date, discharge destination	NS	Missing data is inevitable when collecting large amounts of data, but can be minimised by careful registry design and well engaged partcipants. It takes less than eight minutes to complete the on-line database record. Volume of missing data is a reflection of following factors: 1) how accessible/available the information/data is to whoever enters the data 2) how important/useful the clinician believes the data to be 3) the clarity of the data definitions. To aid data collection, the system offers downloadable PDF forms for each section of the database and for each operation type - these forms can go in the patient notes and be filled in during the patient pathway - data can then be inputted into a computer when the patient is discharged. The data collected enables users to keep track of their cases, edit data, and follow up their patients. There has been an exponential growth in the number of data entry since 2006 - reflection on a) enthusiasm of bariatric surgeons b) 'continued yet slow growth' in the provision of services. Submission of data to the NBSR has recenty become a condition for NHS commissioning of bariatric surgery so in the future the NBSR should contain data on all NHS funded bariatric surgery patients. This has increased number of contributing surgeons from 84 to 150 and number of contributing hospitals from 89 - 129. Whilst submission of data for privately funded patients is not yet mandatory, it is anticipated that data for most of these patients will be included. Colour coding system highlights records that are incomplete. Other tools have been used to make it easier to input data: multi-choice tick	77% of UK Bariatric surgeons were entering data and upto 78% of NHS patients were being recorded into the registry. The degree of completeness for comorbidity data for the NBSR has improved over time. 80% had a complete set of comorbidity data recorded , and just over 10% had only 1 field missing. In the NBSR, it appeared that the comorbidity data entry points that were perceived to be more important were filled in more often than those perceived to be not as useful eg HTN had a high completeness rate, depression and liver disease had a lower completeness rate. 18283 surgical procedures recorded in the database (procedures performed between 2011-2013)	Annual reports. To conform with DOH, surgeons agreed for submitting and reporting of their own mortality data in the interest of openness and transparency	Weight loss surgery Information and Support (WLSinfo) - is a patient led charity. They were invited to contribute the introduction of the report. The charity was very happy to be involved and we re-assured by the outcomes RE mortality, mobidity and LOS. They were also reassured about their chosen surgeon	How to improve follow up of patients is a key challenge	Gives insight into trends of practice and overal outcomes. Help give information on clinical and cost effectiveness. Helps compare interventions in terms of outomes. Helps provide follow up data	NS	Data are anonymised to comply with UK data protection laws. The registry is hosted on a secure Dendrite server. To gain access to data, add, edit data, each user must have their own ID and password. Each user can only see their own data. Access to the database as a whole is restricted to the system administrator

boxes, drop down lists, limiting free-text boxes as much as possible, hover tip prompts to assist users, auto-calculations (eg for BMI), on screen data validation checks, soft mandatory fields (so the user is warnes of incomplete key fields when moving to another screen, automated production of operation notes and clinic letters, auto save features, visual cues to help users know which part of the database they are in (eg gastric bypass screen). During the follow up consultations, doctors and nurses can enter the follow-up data in real time during the clinic visit. The software can then generate an automated follow-up letter which will include, procedure details, weight loss over time (as a graph), comorbidity status and progress

19	Ludman P.F.	The UK transcatheter aortic valve implantation (TAVI) registry: one of the suite of registries hosted by the National Institute for Cardiovascular Outcomes Research (NICOR)	2012	UK TAVI Registry	Transcatheter Aortic Valve implantation surgery	Collaborative approach between stakeholders, with representation from the professional specialist societies (cardiologists via the British Cardiovascular Intervention Society (BCIS), and cardiac surgeons via the Society of Cardiothoracic Surgeons (SCTS)), those involved in data collection and management (the former Central Cardiac Audit Database (CCAD) group, and representatives from the Department of Health (England), the National Specialist Commissioning Advisory Group, and the National Institute for Health and Clinical Excellence	TAVI Steering group. The UK TAVI Group comprises four subgroups: the Steering Group, the Data Management Group (DMG), the Clinical Research Group and the Dataset Group. The Steering Group provides overarching intellectual and professional leadership, and oversight of the developing UK TAVI programme. The DMG acts as custodians of the data, with responsibility for planning analyses and helping in the development of scientific manuscripts. The DMG also acts as a review panel for initial screening of academic requests for access to the TAVI dataset. The role of the Clinical Research Group is to develop and encourage academic analysis of the TAVI database, with plans to develop risk modelling specific to this new intervention	To help guide the commissioning of procedures. To provide a detailed and accurate description of the way this evolving technology is being used to treat patients, to describe the results of this treatment and to be reassured that it is being undertaken as safely as possible. It is hoped that the registry will ultimately improve the care of patients by guiding the therapy to those who will gain most benefit, and benchmarking TAVI units so that all can learn from the best practice of others. It is hoped that comprehensive clinical and outcome data, such as that collected since the first TAVI procedure was performed, may be used to inform the safe introduction of other new technologies	NS	Initial funding for the UK TAVI steering group was provided by the National Specialist Commissioners. As a part of the NICOR suite of cardiovascular audits, additional resource and funding now comes from the Department of Health. The costs of local data entry are borne by the participating hospitals. Funding is independant of industry.	Need to achieve a balance between the size of the dataset and the willingness and ability of data entry teams to collect it accurately. The Dataset Group devised the original TAVI dataset of a UK RCT and is responsible for delivering new iterations and ensuring the change control process	Patient demographics, indications for TAVI, risk factors for intervention, details of the operators, technical aspects of the procedure, and adverse outcomes, including complications up to the time of hospital discharge, there are six additional fields provided for 1- and 3-year follow-up.	TAVI data collection was initially run centrally by the CCAD (Central Cardiac Audit Database) team, along with its other major UK cardiac audits. In 2011, CCAD became part of the newly established National Institute for Cardiovascular Outcomes Research (NICOR) , which, in addition to the TAVI registry, also hosts a number of other national cardiovascular registries. A web browser-based interface has been developed to allow data entry and encrypted transfer to central servers at NICOR. This is available to all centres free of charge. For centres using their own database systems, all that is required is for these systems to generate a comma-separated-values file of a specified format. This can then be sent securely via the web browser interface to the NICOR servers. The National Health Service (NHS) number provides a unique identifier for any person registered with the NHS in England and Wales	Making commissioning of procedures conditional on data collection. Staff at NICOR provide telephone support via a help desk for technical issues and, together with the TAVI Steering Group members, respond to queries regarding case scenarios and definitions. A secure drop box can be used to analyse potential technical problems related to data uploads, file structures and field mapping errors. The commissioning framework in 2009 includes the following statement: 'Mandatory collection of key data will be required from all UK centres in which the procedure is undertaken, in the form of a registry. The registry will include all new patients undergoing the procedure, as well as those who have already received it. Continued funding of TAVI centres will be dependent on compliance with data collection and submission.' Thus, strong professional and commissioning pressure was applied to encourage data collection. In addition, some of the initial funding from the commissioners for the TAVI group was ring-fenced to provide support staff at NICOR whose main remit was to liaise with all TAVI centres and their data entry personnel to assist with timely and accurate data entry. A data completeness report is sent regularly to all centres so that areas for improvement can be readily identified	To date, very high levels of completeness have been achieved, with only one hospital failing to participate fully. For data relating to procedures undertaken before the end of 2010, completeness of valid data was 99.6% for demographic data, 96.4% for risk factors, 97.4% for procedural variables and 98.5% for in-hospital outcomes. Mortality tracking was achieved in 100%. There is no external data validation, however, range checks are applied to appropriate fields. Missing and extreme values and data inconsistencies are queried by direct contact with the TAVI centre. Reliance is placed on local data entry and clinical staff to ensure data accuracy	Initial publication efforts focused on the analysis of all data from the start of TAVI in the UK (2007) to the end of December 2009	NS	Making changes to the dataset risks losing collection from some units whose ability to modify data collection software is limited. Other than mortality tracking, the accuracy and completeness of the data are dependent on the individual centre's efforts, and other than range checks and checks for internal validity, there are no external validation processes in place. While we believe that centres make great efforts to submit accurate data, the lack of validation in such registries does constitute a weakness. Also, apart from life status, later clinical and quality-of-life follow-up is limited. Nevertheless, planned linkage with the other NICOR registries will allow determination of many important future events, such as recurrent need for later cardiac and cardiothoracic surgical interventions	The main strengths are the inclusion of all consecutive patients treated in the UK, regardless of device manufacturer or access route	NS	Researchers do not have access to any patient identifiers. A data-sharing agreement containing a data-governance framework has been created, and is available from the NICOR web site. Through this mechanism, the dataset is available to other research groups, under the guidance of the DMG (Data management group). The DMG acts as a review panel for initial screening of academic requests for access to the TAVI dataset
20	O'Dowd A.	Government considers a national implant register in review of cosmetic procedures	2012	BMJ news article	Cosmetic surgery	NS	NS	BMJ News article that discusses regulation of cosmetic surgery interventions including a potential national register	NS	NS	NS	The information could include the date and place of the operation and the clinical outcome, as well as a method of identifying the patients who received the product	NS	NS	NS	NS	NS	NS	Can act to protect patients from harm	NS	NS

21	Armitage J.N. Irving S.O. Burgess N.A.	Percutaneous nephrolithotomy (PCNL) in the United Kingdom: Results of a prospective data registry	2012	BAUS PCNL data registry	Percutaneous nephrolithotomy (PCNL)	NS	The British Association of Urological Surgeons (BAUS)	To provide important information on current practice incldluing outcome data for PCNL in the United Kingdom. To facilitate personal audit against national outcomes. To be used by surgeons when counselling patients about the treatment options for their renal stone. To establish national standards for this procedure	Web-based system	NS	NS	Unique patient identifier, demographics, procedural data. Effectiveness was measured using stone-free rates defined as "no visible stone on imaging." Stone-free rates were assessed intraoperatively, on the first postoperative day, and at outpatient review using radiography, complications, case complexity, operating surgeon, operating date. Stone characteristics, patient positioning	The registry is prospective, and surgeons are encouraged to submit data at the time of surgery and record complications as they arise. A possible method of improving case-mix adjustment would be through linkage of the data registry with the Hospital Episode Statistics (HES) database of the Department of Health. HES data could be used to validate registry data, verify completeness, and provide information on outcomes such as readmission rates, 30-d mortality, and long-term outcomes. This will help to inform standards and may allow the generation of national guidelines for PCNL	Advertising at national urological meetings. It is in surgeons' interests to ensure the data they submit are complete and accurate given that alternative and perhaps less reliable data sources may be used by others to evaluate their performance. Completeness is likely to improve as more urologists become aware of the data registry and a greater emphasis is placed on personal audit	January 1, 2010, and September 16, 2011, 57 consultant urologic surgeons from 50 centres contributed 987 patients who had 1028 PCNL procedures. Not fully complete data: In 2010, 485 records were added to the data registry. In a similar 1-yr period between April 1, 2009, and March 31, 2010, a study that used data from the Hospital Episode Statistics database of the Department of Health recorded 1732 PCNL procedures in England. Completeness is likely to improve as more urologists become aware of the data registry and a greater emphasis is placed on personal audit	NS	NS	Data is submitted voluntarily, therefore unlikely to capture all procedures. It is possible that those surgeons motivated to submit data to the registry had better outcomes than those who did not record their procedures, which may affect findings. The voluntary nature of data submission may have led to the underreporting of some complications.	BAUS PCNL data registry has provided an important insight into contemporary PCNL practice in the United Kingdom. It has helped to inform national outcomes for effectiveness and safety and will assist surgeons with personal audit	NS	An individual record that contained both a unique patient identifier and National Health Service (NHS) number was created for each PCNL procedure
22	Goldberg A.J. MacGregor A. Spencer S.A.	An information revolution in orthopaedics	2012	Review article	NS	Clinicians must be involved in registry development. It is important for 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. DOH and governement must also be involved in registry process aswell.	NS	This review looks at the sources, quality and interpretation of the electronic databases, as well as the potential benefits for surgeons and their patients	NS	NS	NS	NS	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. HES data cover every inpatient episode, and linkage with other datasets can allow sophisticated approaches to case-mix adjustment. NHS	Make it easy to use the system using intuitive diagnostic and procedure terms that are more familiar to the clinician. Good registry data will help clinicians in their revalidation process and reduce preparotory time - in an appropriately designed system, data on a surgeon's workload, complications, NJR data and all assessments should all be readily available	Initially participation in NJR 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 on a surgeon's workload, complications, NJR data and all assessments should all be readily available	It is challenging to present the registry data to the public in a way that will enable them to exercise choice. "When considering an elective intervention, two questions are important to the patient: 1)'What sort of outcome can I expect from this procedure?' and 2) 'Where is the best place to go for the optimal outcome?' At present the answers to these two questions are nearly impossible to find."	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	Registries provide implant surveillance and related patient outcomes. 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, which was withdrawn in 2010 following a device alert by the Medicines and Healthcare products Regulatory Agency (MHRA). During the first four years of the National Hip Fracture Database, real-time feedback from continuous audit has driven huge improvements in patient care and also led to changes in national policy. There is no doubt that good-quality data can	Both the completeness and the accuracy of the data are critical determinants . Important to be able to analyse the data in the registry appropriately and for the registry to present the data in an appropriate way	NS

											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. This rarely happends in the NHS. The electronic data collection 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. 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						improve care, as demonstrated by the cardiac surgeons from England who now boast one of the lowest mortality rates for cardiac surgery in Europe. 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. 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		
Uberoi R. Das N. Moss J. Robertson I.	British society of interventional radiology: Biliary drainage and stenting registry (BDSR)	2012	Biliary Drainage and Stenting Registry (BDSR)	Percutaneous biliary drainage (PTBD) with or without adjunctive stenting	NS	British Society of Interventional Radiology (BSIR)	To assess current practice in the United Kingdom and use the data collected to provide guidance for improvements in patient care	Web-based system	The registry was funded by the BSIR on behalf of its members.	NS	Demographic, pre- and postintervention laboratory data, technical and clinical outcomes at discharge, known diagnosis, indications for procedure, procedural information, antiobiotic prophylaxis, general anaesthetic/sedation, complications (morbidity and mortality)	Collection and analysis was performed by Dendrite Clinical Systems Ltd. utilising Microsoft Access, Excel, and Crystal Reports XI from business objects software.	Appropriate time and resources need to be allocated to allow good quality data collection, which should form an essential part of medical practice to maintain high standards	From November 1, 2006 to August 19, 2009: 833 procedures were recorded and entered by 62 operators from 44 institutions within the United Kingdom	NS	NS	Time pressures and other NHS commitments act as a disincentive. One of the major deficiencies of the registry was that the cause of death was not established, this will be one of the goals of future data collection and analysis. Data quality and completeness is a significant concern in this registry, which represents a prospective voluntary data collection. A criticism of voluntary registries is that data entry often is incomplete and they represent a nonconsecutive patient group and may not be representative of the entire treated patient population. It is likely that some questions and the terminology used were not clear to all operators. For example, operators were asked to stratify patients' complications into minor and major.	NS	NS	NS

Larsson S. Lawyer P. Garellick G. Lindahl B. Lundstrom M.	Use of 13 disease registries in 5 countries demonstrates the potential to use outcome data to improve health care's value	2012	A review of 13 registries in 5 countries (including UK)	NS	NS	NS	To learn how registries function and to identify any mechanisms by which they are able to influence clinical practice.	NS	NS	NS	NS	In the registries analysed in this paper, the authors note the existence of computerized error-checking routines that immediately flag any entries that are outside normal ranges or inconsistent with previous data for a particular patient. Other data-checking systems include monitor visits to randomly selected hospitals to assess data accuracy	NS	NS	NS	NS	NS	Registries that track patient outcomes improve quality of care. Registries make it possible to assess comparative performance and increase cost effectiveness. A quoted study concluded that by investing $70 million annually in disease registries, data analysis resources, and information technology infrastructure, Sweden could reduce its annual growth in health care spending from an estimated 4.7 percent to 4.1 percent. The estimated cumulative return totaled more than $7 billion in reduced direct health care costs over ten years. Since then the Swedish government has made the expansion of Sweden's network of registries a national priority and has committed to increasing its direct financial support for registries nearly fivefold—from $10 million to $45 million per year—by 2013. Registries can help identify the highest performing implants - this in turn has been found to reduce revsion rates and complication rates with massive cost savings. This study found that the existence of registries was associated with major improvements in health outcomes. Registries do not simply collect data, they promote transparency and make the data transparent	NS	NS

25	Moat N.E. Ludman P. De Belder M.A. Bridgewater B. Cunningham A.D. Young C.P. Thomas M. Kovac J. Spyt T. MacCarthy P.A. Wendler O. Hildick-Smith D. Davies S.W. Trivedi U. Blackman D.J. Levy R.D. Brecker S.J.D. Baumbach A. Daniel T. Gray H. Mullen M.J.	Long-term outcomes after transcatheter aortic valve implantation in high-risk patients with severe aortic stenosis: The U.K. TAVI (United Kingdom transcatheter aortic valve implantation) registry	2011	UK TAVI Registry	Transcatheter Aortic Valve implantation surgery	Society for Cardiothoracic Surgery in Great Britain and Ireland and the British Cardiovascular Intervention Society, Central cardiac audit database (CCAD)	Society for Cardiothoracic Surgery in Great Britain and Ireland and the British Cardiovascular Intervention Society	Aim of registry: To coordinate and monitor the practice and dissemination of TAVI. The purpose of this project was to define the characteristics and clinical outcomes of the patient population treated with TAVI (regardless of technology or access route) in every (i.e., nonselected) center undertaking TAVI	By society for Cardiothoracic Surgery in Great Britain and Ireland and the British Cardiovascular Intervention Society. Web-based system.	NS	Society for Cardiothoracic Surgery in Great Britain and Ireland and the British Cardiovascular Intervention Society agreed on the dataset	Demographics, risk factors, and outcomes, complications (morbidity and mortality)	Mortality tracking was undertaken by the National Health Service Central Register by using unique patient identifiers. It is a legal requirement for all deaths in the United Kingdom to be registered with this body. It is not possible to effect any form of burial/cremation or similar process for the deceased without such registration. Thus, tracking yields very robust results. Survival status for the whole cohort of patients was determined through the NHS Central Register. All fields were examined for missing data or extreme values, and contributing units were asked to complete or correct data where possible. Extreme data were verified and excluded only if found to be erroneous	NS	Data from 877 implants in 870 patients were submitted to the CCAD. Completeness of valid data was 99.6% for demographic data, 96.4% for risk factors, 97.4% for procedural variables, and 98.5% for in hospital outcomes. Eighteen of the 25 units had valid data completeness of >98%. Mortality tracking was achieved in 100% of patients. The U.K. TAVI Registry is unique in that it has captured every TAVI performed at all the 25 active units within England and Wales, and thus includes the entire "learning curve" and early experience of adopting centers without any publication bias that might be induced by center selection	NS	NS	Whereas data on the numbers of procedures and survival outcome are believed to be extremely robust, those concerning morbidity and complications are likely less so. Although internal consistency checks have been applied, these data are self-reported and have not been systematically validated or independently adjudicated	The registry encompasses a substantial number of implants with both commercially available technologies utilizing all of the described access routes, and has robust (100%) overall mortality tracking. It is also the first report of outcomes beyond 1 year for a substantial number of patients (>850)	NS	All processes performed in compliance with current U.K. Data Protection and Information Governance legislation. All patients provided signed, informed consent. Data is encrypted before transfer to central servers
26	Moller H. Richards S. Hanchett N. Riaz S.P. Luchtenborg M. Holmberg L. Robinson D.	Completeness of case ascertainment and survival time error in English cancer registries: Impact on 1-year survival estimates	2011	Research paper	Colorectal, lung, and breast cancer patients	NS	NS	This study linked routine cancer registration records for colorectal, lung, and breast cancer patients with information from the Hospital Episode Statistics (HES) database for the period 2001–2007. Based on record linkage with the HES database, records missing in the cancer register were identified and the completeness of the cancer registers were assessed	NS	NS	NS	NS	NS	NS	Completeness of case ascertainment in English cancer registries is high, possibly as much as 98–99%, when evaluated against independently recorded hospital episodes which included relevant cancer diagnosis and surgery codes. There was 1–4% incompletenes s in the Thames Cancer Registry. Most registries had higher completeness than Thames	NS	NS	NS	NS	NS	NS

Van Gijn and van De Velde	Quality assurance through outcome registration in colorectal cancer - An ECCO initiative for Europe	2011	Commentary	Colorectal cancer	NS	NS	This article describes a strong audit framework for surgical oncology in Europe	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	Hospitals and surgeons can improve their results by learning from their own outcome statistics and those of their colleagues. Identifying, communicating and adopting 'best practices' may improve the quality of care nationwide. The most important advantage of these audit registries compared with clinical trials is the fact that they include the entire patient population without excluding certain patient groups. Benefits of these registries can be seen across Europe. For example In 2001, The Association of Coloproctology of Great Britain and Ireland (ACPGBI) started the National Bowel Cancer Audit Programme (NBOCAP). In 2008, 95% of trusts in England and Wales submitted data. Within 5 years, 30 day mortality dropped from 7% to 4.5%. National audit registries in surgical oncology have led to improvements with a greater impact on survival than any of the adjuvant therapies currently under study. Moreover, they offer the possibility to perform research on patient groups that are usually excluded from clinical trials such as the elderly	Data has to be prospective, complete, case-mix adjusted and preferably collected by independent investigators	NS

28	Berven S.H. Yaszemski M.J. Newton P.O. Christianson W. Aberman H.M. Moreau J.-C. Mulcahey M.J. Betz R.R.	Introduction of new devices and technologies into a spine surgery practice: A review of processes and regulations	2010	Review article that discusses how to bring new technologies and devices to market	Spinal Surgery	A long-term registry need partnership between surgeons, professional societies, and industry to assess the safety and efficacy of new devices and technologies over time	NS	To assist surgeons in building a knowledge base to evaluate whether the new options are appropriate for their patients	A long-term registry recording outcomes measures needs to be developed in a partnership between surgeons, professional societies, and industry to assess the safety and efficacy of new devices and technologies over time.	NS	NS	Registries should be designed to document validated outcome measures, including QOL, length of stay	NS	NS	British Scoliosis Society was asked about compliance of data entry by surgeons within their society, and it is considered to be extremely poor. In the United Kingdom, the hip surgery registry works well	NS	NS	NS	NS	NS	NS
29	Bridgewater B.	Cardiac registers: The adult cardiac surgery register	2010	The Adult Cardiac Surgery Register	Adult cardiac surgery	Clinicians, Society for Cardiothoracic Surgery (SCTS), Central Cardiac Audit Database (CCAD)	Society for Cardiothoracic Surgery (SCTS)	To measure the quality of care of adult cardiac surgery in GB and Ireland and provide information for quality improvement and research	Software systems set up by the Central Cardiac Audit Database (CCAD, now part of the NHS Information Centre	HQUIP funded the paper - not specified who funded the registry	The dataset was selected by the SCTS and the current definitions were agreed in 2003 with an understanding that these would remain unchanged for 5 years to allow data collection to become embedded and to prevent frequent and potentially costly software upgrades.	Preoperative patient characteristics, operative details and postoperative information, including postoperative complications, length of stay and mortality. The dataset allows adjustments to be made for case mix	There is a voluntary validation system - Site visits occur to look at an institution's processes. These include validating documented systems and responsibilities for collecting the audit data, appropriate and timely feedback of data to clinicians for 'real time' feedback, a process to cross reference surgical activity in the SCTS database against theatre logs and the administrative database and a mechanism to cross check mortality on the database against other sources of mortality within the hospital. The data collected by units is uploaded to CCAD after encryption of all patient identifiers. On upload a report is produced about the number of records and potential major and minor flaws in the data to allow correction to be made. They are able to measure long term mortaility because all patient records in the database have an 'encrypted' NHS number that allows linkage with the office of National Statistic to allow life status at any time to be established. Important to have a data validation processes, possibly with online screening of submitted data	The data enables individual practitioner recertification. The White paper 'Trust, assurance and safety' is changing the way the medical profession is regulated, and demonstrating satisfactory 'success rates of treatments' is becoming essential. This thought process increases the importance of, and clinical buy-in to, national registries. There was initial reluctance from some within the specialty to conduct data collection, collation, analysis and publication, but a combination of leadership within the profession and external scrutiny has driven the initiative so that robust and complete information is now available	The data in the database is thought to be of good quality but this is not subject to rigorous external validation. It is believed that case ascertainment is complete, certainly for the NHS hospitals. The completeness rates of the submitted data are generally good—the incidence of missing data for age is 1.4% and for gender 0.07% between 2004 and 2008. Most important fields for risk stratification have an incidence of missing data of <5%. The missing data for postoperative complication rates is somewhat higher at around 15%. This is coming down over time. The recent database report included over 400 000 operations with information on over 114 000 coronary artery bypass operations, 30 000 aortic valve operations and 10 000 mitral valve operations, which allowed important findings to be reported	The CCAD software allows views of the data including activity, the incidence of various risk factors, in-hospital mortality, risk-adjusted mortality, postoperative complications rate and length of stay. The highest profile outputs from the database have been the national reports, known within UK cardiac surgery as the 'blue books'. These are comprehensive reports which exhaustively document trends in cardiac surgery outcomes and practice and benchmark cardiac surgical mortality rates, including longer-term outcomes. Another high-profile output from the database is the publication of named hospital and surgeon mortality data to the public through the Care Quality Commission website. This presents detailed information about cardiac surgical diseases and their treatments, and presents results in a clear way for patients and their carers. This website receives in excess of 26 000 'hits' each month. SCTS is developing a	Outcomes of care by a consultant team should be available to the public as per Professor Sir Ian Kennedy's report, following events in paediatric cardiac surgery at Bristol Royal Infirmary and the subsequent public inquiry. Mortality data for this registry are available to the public. Data has been used for patient information and patient choice.	Time pressures act as a disincentive. Registry may produce risk averse behaviour due to publishing surgeon specific outcomes. The registry was not subjected to rigorous external validation and there is a important incidence of missing data in some critical fields within the dataset. The SCTS has also not been able to frequently modify the dataset to account for changes in contemporary practice, which prevents accurate tracking of activity and analysis for novel and emerging treatments	The registry has been linked with marked improvements in outcomes, without many of the feared adverse consequences	NS	The reports also have political significance—for example, the 5th report contextualised the UK cardiac surgical data collection initiative against the recommendations of the public inquiry into the events at Bristol Royal Infirmary. The recent 6th report was used to help inform thoughts on the professional recertification agenda. The registry uses encrypted patient identifiers

to look for hospitals of potential concern, followed up by targeted site visits to assess accuracy of data entry .

strategy to increase the research outputs from the database and has activated a data-sharing agreement for that purpose. There has been much debate over publishing named surgeon data, but what is without question is that there have been marked improvements in risk-adjusted mortality for cardiac surgery in the UK over the past 10 years. There is no evidence that the initiative to collect, benchmark and publish these data has been associated with significant 'risk-adverse' behaviour among surgeons in the UK. This should be reassuring to all stakeholders

Bates T. Kearins O. Monypenny I. Lagord C. Lawrence G.	Clinical outcome data for symptomatic breast cancer: The breast cancer clinical outcome measures (BCCOM) project	2009	Breast Cancer Clinical Outcome Measures (BCCOM) Project	Breast cancer	Association of Breast Surgeons, the UKACR (UK Association of Cancer Registries), Breast surgeons	BCCOM Steering Group	To capture monitor current practice of treatment of symptomatic breast cancer	By BCCOM Steering Group	Breakthrough Breast Cancer (charity)	Uses a subset of the national breast cancer data set. A breast cancer data set was designed after consultation with the ABS (Association of Breast Surgery) and the UKACR (UK Association of Cancer Registries). QOL and PROMS data should become part of the dataset in the future.	Demographics, diagnostic information, tumour characteristics,surrogate outcome measures: 1) Number and proportion of breast cancers for which complete information is received 2) Number of symptomatic and screen-detected breast cancers treated in a hospital per annum 3) Number and proportion of breast cancers for which there is a pre-operative diagnosis 4) Number and proportion of breast cancers given medical treatment only 5) Number and proportion of breast cancers treated surgically 6) Mastectomy rate by breast size: <15; ⩾15 and ⩽20; >20 and ⩽35; >35 and ⩽50; >50 mm invasive diameter 7) Number and proportion of invasive breast cancers for which nodal status is known 8) Number and proportion of histologically node-negative invasive breast cancers for which more than seven nodes were harvested 9) Number and proportion of invasive breast cancers treated by breast-conserving surgery and receiving radiotherapy 10) Number and proportion of node-positive patients with invasive breast cancers, aged <60 years, receiving chemotherapy, number and proportion of patients with ER-positive invasive breast cancers, receiving hormone therapy	Data on all newly-diagnosed primary symptomatic breast cancers are obtained from the UK cancer registries. To validate the accuracy of data collection, cancer registries send the collected data to the concerned consultant breast surgeon. The surgeons in turn are asked to check the validity of data by comparing them with those held on local systems, to make amendments if necessary and to return the data without patient-identifiable details to the BCCOM (Breast Cancer Clinical Outcome Measures) Project team at the West Midlands Cancer Intelligence Unit (WMCIU). Surgeons may submit unchecked data if they do not have the necessary support mechanisms or if they are convinced that the quality of the data is high. Cases are not included if the surgeon attends less than six symptomatic cases in the year, chooses not to participate or is unknown. Cancer registry data are now matched to data held in national data sets, such as Hospital Episode Statistics (HES) - this is useful in collecting data missed by the registry and for cross checking of data	Participation by breast surgeons in the BCCOM Project is not mandatory, but it is strongly encouraged by their professional body, the ABS (Association of Breast Surgeons). The regional symptomatic representatives of ABS are encouraged to review participation in their own areas and to identify ways in which this could be improved	In year 3, 221/488 eligible surgeons submitted data; 16739/32113 cases were submitted. In year 2 (cases diagnosed in 2003), there was a 14% reduction in the total number of cases submitted (14 120 compared with 16 407) and very large reductions in some regions. These decreases are in part because of the more reliable exclusion of ineligible screen-detected cases in year 2, but mainly result from changes in the protocols for data collection in year 2, which required written consent from all surgeons before releasing the data of patients under their care to the lead surgeon in each hospital for validation. In year 3 (cases diagnosed in 2004), the UK cancer registries supplied the BCCOM team with data on all 48 983 diagnosed breast cancers. This provided a denominator of the total number of eligible cases with which participation could be compared and an estimate of the annual breast cancer burden in the United Kingdom could be made. Wales had the highest recruitment of cases at 94%, and the Thames Region, which has the highest number of surgeons and the most number of cases, had by far the lowest recruitment at 29%. In addition to the 1219 cases (3%), which were excluded in year 3 because the surgeon had treated fewer than six symptomatic	NS	NS	Initially, (before the BCCOM project started) the capturing of data on symptomatic breast surgery was not funded; and whilst initially they captured 1/3rd of the population caseload, many collaborators failed to continue owing to lack of funding. Although progress in data collection has been improved by central notification of surgeons in most regions, the data underline the continuing difficulty in depending on the voluntary and active participation of individual surgeons in the submission and validation of data. Surgeons must give written permission for release of patient details - but this has not been good for data completeness	Regular audit of surgical practice improves standards and highlights outliers. This BCCOM audit enabled identification of regional variations in surgical practice	NS	From year 2 onwards, the initial protocol for data collection was modified to ensure compliance with Section 60 of the Health and Social Care Act 2001. It was observed that, although non-identifiable data were stored in the BCCOM central database, the flow of information at the beginning of the audit cycle, from cancer registry to surgeon for validation, was at an individual patient level. Therefore, the updated protocol requested that cancer registries obtain the written consent of individual consultant surgeons before releasing the data to the lead breast surgeon in each hospital. Surgeons must give written permission to for release of patient details - but this has not been good for data completeness

														cases, a further 21 220 symptomatic cases (54% of the total number of symptomatic cases identified by the cancer registries) could not be included either because the surgeon was non-compliant (15 471 cases) or unknown (5749 cases)								
N. Chalmers, K. Jones, K. Drinkwater, R. Uberoi, J. Tawn	The UK nephrostomy audit. Can a voluntary registry produce robust performance data?.	2008	UK national nephrostomy registry	Percutaneous nephrostomy	Royal College of Radiologists Clinical Radiology Audit Sub-Committee (CRASC), British Society of Interventional Radiology	CRASC and NATCANSAT (National Cancer Services Analysis Team)	To investigate the effectiveness of the Royal College of Radiologists Audit Sub-Committee's national prospective registry of percutaneous nephrostomy. The registry aims to enable participants to audit their practice and compare performance with predetermined standards	An initial retrospective pilot audit was undertaken by the CRASC involving case note review. This helped develop the prospective registry. Web-based dataset was designed for rapid completion. The software used was written by National Cancer Services Analysis Team (NATCANSAT) who created a web-based application, providing a standardized approach to data collection, with the use of drop down menus and a minimum of free-text fields, and avoiding the need for participants to download or install any software. The website was written in Microsoft ASP and data was stored in a Microsoft Access database (www.microsoft.com). NATCANSAT also provided telephone and e-mail helpdesk support to participants between the hours	NS	Have a compromise between ease of data collection and thoroughness. Use of drop down menus and a minimum of free-text fields.	Potential risk factors, operator experience, indication, timing of precedure (in/out of hours), side of operation, procedural data, procedure success, precedure repeat rate, complications	National Cancer Services Analysis Team (NATCANSAT) (www.canceruk.net) was commissioned to write the software to support the data collection process. A registry in which external bodies could have confidence would require independent validation of data entries for accuracy and completeness. This would require significant investment in resources and a higher degree of commitment	The web-based dataset was designed for rapid completion with a compromise between brevity and thoroughness. Data could be entered via use of drop down menus and a minimum of free-text fields, and participants didn't need to download or install any software. There was also telephone and e-mail helpdesk support to participants between the hours of 9 am–5:30 pm Monday–Friday	3200 cases were accumulated over a period of 26 months - this is far from a complete sample of national practice. A few departments contributed data on all, or nearly all, their cases. A larger number of hospitals contributed only a small proportion of their cases and most contributed none at all. Fewer than 30% of the acute hospitals that were contacted contributed any data	NS	NS	Objective independent scrutiny of each operator's returns is impossible, so there is no way to assess the completeness and accuracy of the submitted data. Therefore, it is impossible to know how representative the data are. Despite efforts at the outset to produce a simple dataset, it is apparent that some contributors interpreted the form differently from others. This demonstrates the near-impossibility of devising a form that is unambiguous, while at the same time maintaining brevity such that individuals are not deterred from contributing by the length of the form. The data are not sufficiently robust to permit patients, purchasers, or regulatory authorities to make any inference about the standard of nephrostomy provision of any centre	Individual doctors have a duty, defined by the General Medical Council, to audit their own performance. Registry lets you do that	NS	Data was stored in a Microsoft Access database. For confidentiality reasons, no patient identifiable data items, such as name, NHS number, or address/postcode, were recorded

							of 9 am–5:30 pm Monday–Friday for the duration of the audit													
Clarke D.R. Breen L.S. Jacobs M.L. Franklin R.C. Tobota Z. Maruszewski B. Jacobs J.P.	Verification of data in congenital cardiac surgery	2008	This paper reviews 3 registries: The Society of Thoracic Surgeons, The European Association for Cardio-Thoracic Surgery, and The United Kingdom Central Cardiac Audit Database. We will only extract data on overall lessons learnt and specific registry info from the UK registry	Congenital cardiac surgery	NS	NS	This paper reviews the current strategies used for verification of the data in the congenital databases of The Society of Thoracic Surgeons (america), The European Association for Cardio-Thoracic Surgery (europe), and The United Kingdom Central Cardiac Audit Database (UK). The Central Cardiac Audit Database aimed to provide national analyses of outcomes after cardiovascular surgery and therapeutic catheterization	NS	The UK registry is funded by DOH	NS	NS	For UK registry (The Central Cardiac Audit Database): Data are collected electronically in an anonymous encrypted format with prospective tracking of mortality and re-intervention using up to a 40 field minimum dataset. In the UK registry, the verification process begins at the congenital cardiac centre. Most of the 13 cardiac units in the United Kingdom have database managers who check for data accuracy with medical staff before the data is submitted. Independent validation of the patient's status (alive or dead) is achieved by central tracking using the linkage of each patient's National Health Service number to the Office of National Statistics, where the death of every resident in England and Wales is registered. Data verification audit site visits are very effective at drawing attention to the importance of high quality data. The visits can also provide "ammunition" for convincing institutional administration to commit appropriate resources to data management. In the UK registry, each unit is visited for one/two days each year by a specialist database nurse administrator from the Central Cardiac Audit Database and a volunteer surgeon or cardiologist from another unit. A detailed pre-visit proforma is	The audits can benefit participating centres by validating methods that are effective and by identifying ineffective practices and providing suggestions for improvement. Public interest in medical outcomes is at an all time high and increasing focus on "pay for performance" . The need for accurate, complete and high quality Congenital Heart Surgery outcome data has never been more pressing. For the UK registry (Central Cardiac Audit Database), data submission is compulsory for all centres undertaking congential cardiac disease surgery. External monitoring of performance gives an incentive to provide accurate and complete data	NS	For the UK registry centre specific results are now published on the World Wide Web allowing free access to families and the media	NS	For the UK registry: ideally, every medical record of the approximately 8,000 patients undergoing procedures each year should be examined. However, there is a lack of funding and skilled manpower for such an activity	Patients included in medical audit have better outcomes than those not included	NS	In the UK registry, patients give informed consent for data submission

completed by each centre covering such areas as security and confidentiality, in-house verification and quality assurance, training for data collection and accuracy, communication issues, accountability, health records management, and timeliness of central submission. The visits are scheduled in the year following data submission. At the visit, all operating room and catheter laboratory logbooks are scrutinized to ensure procedural data accuracy and that all procedures have been captured. Also, a random selection of 20 patient hospital records is requested in advance and compared to the dataset submitted for missing or incorrect data. A Data Quality Indicator score is then calculated. The results have been encouraging with the scores improving over time from an average of 79% to 91% currently (range 81–98%). At the end of the visit, the unit clinicians meet with the auditors to discuss areas of excellence and deficiencies. Within weeks, a formal report is submitted back to the hospital team and to higher management. The visits are therefore seen by the congenital cardiac clinicians as very positive encounters. A combination of site visits to verify the data at the primary source of the data, and external verification of the data from independent databases or registries, such as governmental death registries, may be required to allow for optimal verification of data. It is important to verify the completeness and accuracy of data in congenital cardiac registries - A report from the United Kingdom Central Cardiac Audit

Database reveals that hospital databases under-reported 42 operative deaths out of a total of 194 (21.6%). Similarly, the European Association for Cardio-Thoracic Surgery implemented a data verification process and discovered that 7 hospital deaths out of 68 (10.3%) were not reported.

Jacobs M.L. Jacobs J.P. Franklin R.C. Mavroudis C. Lacour-Gayet F. Tchervenkov C.I. Walters H. Bacha E.A. Clarke D.R. William Gaynor J. Spray T.L. Stellin G. Ebels T. Maruszewski B. Tobota Z. Kurosawa H. Elliott M.	Databases for assessing the outcomes of the treatment of patients with congenital and paediatric cardiac disease--the perspective of cardiac surgery	2008	Central Cardiac Audit Database (UK)	Congenital cardiac surgery	The Central cardiac audit database was formed in collaboration with the British Cardiac Society, the Society of Cardiothoracic Surgeons, and the British Paediatric Cardiac Association	Respective society of the surgical specialty	This review discusses the rationale for the creation and maintenance of multi-institutional databases for congenital heart surgery, together with a history of the evolution of such databases. This review also describes several European and North American databases for pediatric and congenital cardiac surgery as well as the UK Central Cardiac Audit Database. We have collected data on general learning points and specific information on the UK Central Cardiac Audit Database. The UK Central Cardiac Audit Database monitors surgical and transcatheter cardiovascular interventions undertaken on patients with congenitally malformed hearts	The development of the Central Cardiac Audit Database involved the establishment of a team of experts to set up the computerised registry with robust protocols for the protection and validation of data. Electronic data collection (encrypted)	For the Central Cardiac Audit Database, funding is centrally from the DOH	There was an International Congenital Heart Surgery Nomenclature and Database Project in September 1998. This led to the publication of a common nomenclature and a common core minimal data set that were enthusiastically accepted by the majority of cardiac databases/societies worldwide. While it is useful to collect data on mortality, fortunately most patients do not die - it is therefore very important to collect data on morbidity , resource utilisation, QOL. A common clinical language (nomenclature) is fundamental for registry success	Demographics, risk factors, co-morbidity, diagnosis, procedure, mortality, complications, length of stay, time to extubation, and utilization of resources, For the Central Cardiac Audit Database, there were initially 20 data fields. After 2 years there was a gradual expansion of the fields - now there are 40 data fields	Independent validation of the status of the patient as alive or dead is achieved by central mortality tracking using the linkage of the National Health Service number of the patient to the Office of National Statistics. For Central Cardiac Audit Database annual visits for the validation of data are undertaken to each hospital submitting data to ensure accuracy of the data and that all procedures undertaken have been captured. These visits also help identify how to improve database management. Whilst site visits are expensive and time consuling, they are essential	For the Central Cardiac Audit Database, there were local "audit facilitators" that encouraged clinicians to enter data and to validate the quality of data before submission. For the Central Cardiac Audit Database, it is compulsory for all centres carrying out interventions on patients with congenital cardiac malformations to submit their data	For Central Cardiac Audit Database, over 26,000 surgical procedures have been amassed at a current rate of over 4,500 each year	Annually, the committee responsible for the database of each Society issues to each participating institution a report consisting of aggregate data from all participating groups and institutions, de-identified with respect to source, and of data specific to the participant. Each insitution receives a report of outcomes encompassing all of their annual activity, as well as cumulative activity over the years of participation. Each participant is therefore able to identify trends in their own practice, including outcome such as mortality, complications, length of stay, and utilization of resources. For the Central Cardiac Audit Database (UK), underperforming units would receive constructive feedback, which focused, for example, on surgical techniques, intensive care support, or shortcomings in the 'system' or infrastructure. For the Central Cardiac Audit Database, results have been published on the web, with free access to families and the media providing details of outcomes after major surgical procedures and transcatheter procedures. It is important to reduce the time between the actual clinical event (the operation) and the release of the data. Important to realise that outcomes of extremely complex cases are likely to be less favourable than those of cases of lesser complexity. The recognition of this problem led to the development of a system to stratify operative procedures for congenital cardiac diseases in terms of complexity. The system adjusts for baseline	NS	NS	Events such as the Bristol Royal Infirmary have informed us that we need registry databases to facilitate programs of quality assessment and quality improvement. Furthermore, such events including the sometimes misleading reporting of data of uncertain quality, emphasise the importance of clinicians, with their professional societies to take the responsibility of data analysis and reporting. Enables sharing of data and comparing outcomes with colleagues in other institutions and countries. This helps define areas of weakness to enbale continuous improvement	Registry Databases are distinguished in principle from "Research Databases" in that they are designed to catalogue essential information, in less voluminous detail per patient than is practical in a research database, but with the goal of having this information on all patients. Registry data must be timely, freely available with good degree of data capture. It should contribute to education, research, the allocation of resources, the analysis of outcomes, and the improvement of quality. A successful registry is one in which the data are complete. There are five fundamental elements that are essential to success in a mutli-institutional registry database: 1) a common language or nomenclature, acceptable and familiar to all participants. 2) an established uniform core dataset. 3) a mechanism of evaluating the complexity of the operations. 4) a mechanism to ensure and verify the completeness and accuracy of the data. 5) a platform that enables collaboration between medical and surgical subspecialties.	For the Central Cardiac Audit Database, patients give informed consent for data submission. There are robust protocols for the protection and validation of data. In the UK Central Cardiac Audit Databse, data are submitted in an anonymous encrypted format

														case-mix differences when comparing discharge mortality. The system was created using a combination of judgment-based and empirical methodology with a panel of pediatric cardiologists and cardiac surgeons.						
Knight J.S. Senapati A. Lamparelli M.J.	National UK audit of procedure for prolapsing haemorrhoids on behalf of the Association of Coloproctology of Great Britain and Ireland	2008	National UK audit of procedure for prolapsing haemorrhoids	Stapled haemorrhoidectomy	NS	Research and Audit Committee of the Association of Coloproctology of Great Britain and Ireland (ACPGBI)	To collect prospective data on stapled haemorrhoidectomy	Electronic online database through the ACPGBI website.	Electronic database and online entry process were sponsored by Ethicon Endo-Surgery, but they had no input or access to the data collected.	NS	Data were collected on the grade and symptoms of haemorrhoids, the presence of any external component, previous treatment, grade of surgeon, type of anaesthetic, height of the staple line above the dentate line, length of hospital stay, immediate complications, pain on discharge and any problems encountered at 6-week follow-up, data were collected on the preoperative symptoms of haemorrhoids according to a	Following registration on the website, the surgeon obtained a secure personalised logon through which data were entered real time at the end of the case and at 6-week follow-up	Surgeons invited to enter data on the website. Reminders sent via email and throught the Association's bulletins. This audit can form the basis of a future registry. Such a registry should be compulsory to submit data	695 patients were entered onto the database by 61 UK surgeons (2005). Only 10% of the ACPGBI members contributed data. Data represents only 20% of the potential cases conducted in the UK	NS	NS	Short follow up of 6 weeks - not long enough to detect recurrence. Only 10% of the ACPGBI members contributed data. Data represents only 20% of the potential cases conducted in the UK	Provides a good reflection of current practice	NS	Personalised login for each surgeon

											previously validated symptom severity scoring system, however these data were not collected postoperatively,								
35	Nelson P. Nieuwenhuijsen M. Jensen T.K. Mouriquand P. Hughes I. Wilcox D. Elliott P.	Prevalence of hypospadias in the same geographic region as ascertained by three different registries	2007	Hypospadius surgeons register	Hypospadius surgery	NS	NS	To compare the birth prevalence and ascertainment of hypospadias in a population-based hypospadias case register	NS	NS	NS	Demographics, birth prevalence.	Data sources included waiting lists, surgeons' diaries, operating theatre logbooks and databases, personal records, clinic letters, hospital databases, and private patient records. Data was also collected from the National Congenital Anomaly System (NCAS), and Hospital Episode Statistics (HES). Data were checked for duplication within and between surgical centres	NS	NS	NS	NS	NS	Registry data are vital for congenital anomaly surveillance both for health care planning and also in monitoring the potential impact of environmental chemicals on reproductive health	This registry was relatively successful because it has multiple sources of ascertainment, dedicated staff and resources, and a well designed and quality assured structure	All data were held by the UK Small Area Health Statistics Unit
36	Sharma S. Dreghorn C.R.	Registry of shoulder arthroplasty - The Scottish experience	2006	Scottish shoulder arthroplasty registry	Shoulder arthroplasty	NS	NS	To assess contemporary practice (including number and type of prosthesis), provide a benchmark against which surgeons could compare their practice, identify risk factors for a poor outcome, and to improve outcomes through continuous feedback to the participating surgeons	NS	NS	Participating surgeons agreed on a standardised diagnostic and operation code to facilitate data collection.	Patient demographics, date of surgery, grade of surgeon, indication, Rotator Cuff status, Glenoid deficiency, type of implant used, procedure performed, intraoperative probems (yes/no), complications, postoperative pain, sleep, activity and patient satisfaction (with regards to the results of your operation, do you feel: pleased, satisfied, disappointed) were assessed annually using another standardised proforma with only yes and no answers	The registry was voluntary and relied on a single surgeon (CRD) collecting, collating and providing feedback to the individual contributing suregons. Surgeons were individually contacted by the senior author and encouraged to contribute to the registry. The participating surgeons agreed on a standardised diagnostic and operation code to facilitate data collection. The senior author collated these data on a computerised database (Microsoft Access) and provided annual feedback to the individual surgeons. In order to evaluate the percentage of shoulder arthroplasties performed in Scotland to those registered in the registry, we cross-referenced our data with the data from the Information and Statistics Division of Scotland (ISD), which is based in Edinburgh. ISD gets data from the Scottish medical records (SMR) forms that accompany every in-patient admission in Scotland. The ISD data do, however, rely on accurate coding and therefore its	NS	A total of 451 shoulder arthroplasties were registered over a 5-year period. Cross referencing the data with the data from the Information and Statistics Division in Scotland, we found that 25/200 shoulder arthroplasties performed in 1996, 91/225 cases in 1997, 167/315 cases in 1998, 85/260 cases in 1999 and 41/255 cases in 2000 were registered in our registry. Contributions to the registry increased from 12% of all shoulder arthroplasties performed in the first year of the registry to 53% in the third year. There was then a drop in the percentage of shoulder arthroplasties registered over the next 2 years so that in the 5th year of the registry only 18% of the shoulder arthroplasties performed were registered - this drop was mainly due to financial and time constraints which resulted in the 4th annual registry	Annual feedback given to the individual surgeons	NS	Compliance in data collection. Expense of running a registry (the Mayo Clinic spends about $400,000 annually to maintain its registry). Registry was voluntary and relied on a single surgeon (CRD) collecting, collating and providing feedback to the individual contributing suregons. There were financial and time contraints which led to the 4th annual Registry meeting being cancelled - this resulted in a drop in the percentage of shoulder arthroplasties registered over the next 2 years. The voluntary registrations of data in our registry depended on a small group of dedicated shoulder surgeons who were keen to evaluate their performance and were motivated, albeit for a short spell, to contribute to the shoulder registry. It was logistically difficult to target all the orthopaedic surgeons in Scotland and motivate them to contribute voluntarily to the registry. Another factor for the poor percentage of registration was that orthopaedic surgeons who had no declared interest in shoulder arthroplasty were increasingly performing shoulder arthroplasties. Shoulder surgeons who performed 3 or fewer shoulder arthroplasties were performing 30% of the shoulder arthroplasties	NS	Accuracy and completeness of data entered	NS

												data may not be a true reflection of the number of shoulder arthroplasties performed in Scotland. This registry employs dedicated personnel for data collection, validation and ensuring compliance from the participating surgeons		meeting being cancelled						
Sher J.L. Reed M.R. Calvert P. Wallace W.A. Lamb A.	Influencing the national training agenda. The UK & Ireland orthopaedic elogbook	2005	UK and Ireland Orthopaedic elogbook	Orthopaedic operations	British Orthopaedic Association (BOA) Education Committee, the Specialist Advisory Committee (SAC) in Trauma and Orthopaedics, the British Orthopaedic Trainees Association (BOTA) and the Royal College of Surgeons of Edinburgh (RCSEd)	Responsibility for the project has passed to the BOA eLogbook Validation & Authorisation Committee (eVAC)	To provide data on trainees operative experience and give an insight into their training operative experience in trauma and orthopaedics	Over several years a committed group of trainees and trainers tested several versions of the logbook leading to the current product. Current software was produced by the Faculty of Health Informatics at the RCSEd.	Funds were raised from the BOA (british orthopaedic association), the Editorial Board of the Journal of Bone and Joint Surgery, the Charnley Trust, the Wishbone Trust, Smith & Nephew, Johnson & Johnson and Biomet.	After much debate, a system was devised to encompass the information needed by the United Kingdom and Irish SAC. Users can submit suggestions for unlisted procedures, which once ratified by the eVAC committee (eLogbook Validation & Authorisation Committee (eVAC), appear seamlessly as the users' 'Synchronisation' button is next pressed. The great majority of users' suggestions have been incorporated already.	Trainee level, level of involvement, operation	For data synchronisation, computers 'talk' to each other to check that their data is identical. If not, data is transferred by the main server at the Royal College of Surgeons of Edinburgh	By making the registry a 'thin' client application it means that no software has to be downloaded on to the users computer. Rather the software relies on a live internet connection. This is more advantageous when most people have internet connections. Making the logbook compatible with portable devices. It is compulsory for all specialist registrars to submit the data	Compliance is 92%. Although the database now includes over 500 000 operations, the 2004 data represents 157 492 uploaded operations	The eLogbook gives information on levels of supervision and training opportunities provided by specific trainers, hospitals and training programmes	NS	NS	The database gives information on the training opportunies available and levels of supervision. It also helps compare training posts. This helps gain an insight into the trainees experience over a given time period and compare this against the national average. Training opportunities offered by training programmes, hospitals or trainers can also be compared with national figures. Such comparisons display not only total numbers of procedures but also identify unused potential learning experiences	NS	Because data which is defined as 'sensitive' or 'confidential' by the UK Data Protection Act is collected in the logbook, each user must register with the data protection authorities as a 'data controller'. The RCSEd server uses the same level of encryption security as bank web sites and the data is stored simultaneously on two servers which are regularly backed up off-site. Each user owns their data and collated information is administered by the eVAC committee. Access to the reports is restricted to defined users. Trainees have access to their own and pooled national comparative data. Training programme directors can examine a local individual's performance and individual trainers and hospitals. The SAC chairman has access to all regions and all training departments

38	Thomas S.M. Beard J.D. Ireland M. Ayers S.	Results from the prospective Registry of Endovascular Treatment of Abdominal Aortic Aneurysms (RETA): Mid term results to five years	2005	Registry for Endovascular Treatment of Aneurysms (RETA)	Endovascular aneurysm repairs	NS	NS	To collect long-term data for endovasular aneurysm repairs in the UK	NS	Financial support has been provided by the BSIR and VSGBI and by the following device companies, BARD UK Ltd, WL Gore (UK) Ltd, Medtronic Ltd, Cook (UK) Ltd and Boston Scientific Ltd, and Cordis (UK)	NS	Demographics, ASA grade, stent graft type, fitness for surgery, aneurysm diameter, contraindications, indication for surgery, type of anaesthetic, complication rate, mortality rate, length of stay	A simple one-page follow-up form was sent out to the each centre on an annual basis, this follow up data could be returned by post, fax or via e-mail. Original submission of data was voluntary, and return of follow up data was dependent on the submitting centre in the majority of cases. Centres that failed to return forms were sent a further form, followed by a telephone reminder. The returned follow up data was manually entered into an Access database	Centres that failed to return forms were sent a further form, followed by a telephone reminder	Since its inception in 1996 a total of 1823 cases have been submitted to the Registry. One thousand cases were submitted to the Registry from 41 centres between 1st January 1996 and March 3rd 2000. The number of centres and cases increased each year until the EVAR trial began. Despite the best efforts of the Registry co-ordinator voluntary data submission resulted in returns rates for requested follow up data of 87% at 1 year and 77, 65, 52 and 51% at 2, 3, 4 and 5 years, respectively. Despite the best efforts of the Registry co-ordinator the returns rates we present in this paper fell from 87% at 1 year to 51% at 5 years	NS	NS	The database was voluntary which resulted in reduced data completion. It is very difficult to ensure data is submitted. Data submission to registries is usually voluntary which risks bias in the data submitted. Furthermore follow-up data becomes increasingly difficult to obtain. Despite the best efforts of the Registry co-ordinator the returns rates we present in this paper fell from 87% at 1 year to 51% at 5 years. If a large amount of data is submitted it is likely to be representative of practice at the time it is collected, but the results presented can only ever represent the best estimates within the limitations of the data collected	Registries can be of value in the assessment of new treatments. Regulatory organisations such as the UK National Institute for Clinical Excellence (NICE) will often accept that, in the absence of formal trials, registries can act as a means of assessment of new treatments or technologies. Registry data can provide useful insight into the results of new treatments, and can be used in planning trials and to generate hypotheses to be tested. The collection and analysis of data from registries should facilitate the early identification, quantification and correction of device-related problems	NS	NS
39	Wyatt M.G.	Registries versus trials for the evaluation of the Endovascular Treatment of Abdominal Aortic Aneurysms	2005	RETA registry (UK registry for Endovascular Treatment of Aneurysms)	Endovascular aneurysm repairs	NS	NS	This is a commentary discussing registries versus trials for the evaluation of endovascular aneurysm repairs. It also describes the RETA registry (UK registry for Endovascular Treatment of Aneurysms). Aim of RETA Registry was to audit EVAR deployments within the UK	NS	NS	NS	NS	NS	NS	RETA registry contains both retrospective and prospective data on 1823 procedures	RETA registry annual audit reports are produced on behalf of the Vascular Society of Great Britain and Ireland and the British Society of Interventional Radiology	NS	Registry data is often incomplete and may present a biased view of the overall performance of new technologies. The RETA registry suffers in that it is voluntary and audited in an 'open' fashion, possibly leading to selection bias	Registries can be used to help RCT design. Data from the RETA registry was used in the design of the UK EVAR trials and as an audit tool to assess centres for trial entry. RETA registry has been an invaluable source of data on the performance of EVAR devices	NS	NS

Shakespeare P.G. Bazire N. Whitworth I.H.	The UK breast implant registry - Ten years on	2005	UK Breast Implant Registry (UKBIR)	Breast implant surgery	NS	NS	The initial aim of the Registry was to record the use in the UK of all types of breast implant on a prospective basis	NS	MHRA. It is essential to have long-term funding as data will need to be collected for many years (lifetime expectation of implants is 37 years)	NS	Demographics, indication, implant type	NS	Directories of hospitals with theatre facilities were used to target individual units who might, or might not, be undertaking breast implant procedures. Contacts at responding centres were made, registration forms were prepared and circulated	Since 1993, the number of recorded procedures has risen steadily to reach a peak of approximately 14,000 in the year 2001. UKBIR now has some 80,000 patients registered as having undergone breast implant procedures. This involves in excess of 140,000 implants	Annual reports have been issued for each year of operation. Research projects using the data are being conducted which will help assess implant performance and lifespan	NS	In 2002 the registry started a new registration form in order to gain formal consent from patients regarding their data collection. This registration procedure has made the data collection process more complex resulting in a drop in registrations	UKBIR data can be used to audit process and can provide feedback data to individual centres for audit or information purposes. This registry can be a useful source of knowledge for tracing purposes in any advice on patient safety. The registry will help provide evaluation on breast implant performance and lifetime	The main purpse of a device registry is to describe the performance of implants in the broadest general sense, particularly assisting in the regulatory and safety aspects of implant use. Essential for registry to have good compliance amognst contributing centres	Since its foundation, the Registry has been guided by the Data Protection Act (1984, 1998), the Caldicott confidentiality principles, and guidance published by the General Medical Council (GMC). Upto 2002 there was no formal recorded consent from patients to record their data. Clinicians were asked to ensure that patients knew and agreed that registration would be made but, if a formal note was made, this was only to be found in the patient's notes. Although the Data Protection Act does not require explicit, written consent for personal data to be held, from 2002 the registry started to acquire formal consent from patients over registration and participation in research projects. Registration was with the Data Protection Registrar and confidentiality terms were defined. Individuals registered on the database have a right to all information recorded about them, but the Data Protection registration prevents disclosure of identifying information to a third party - this protects the interests of individuals registered but does allow the development of research projects

41	Biancari F Ruggieri VG Perrotti A Svenarud P Dalen M Onorati F Faggian G Santarpino G Maselli D Dominici C Nardella S Musumeci F Gherli R Mariscalco G Masala N Rubino AS Mignosa C De Feo M Corte AD Bancone C Chocron S Gatti G Gherli T Kinnunen EM Juvonen T	European Multicenter Study on Coronary Artery Bypass Grafting (E-CABG registry): Study Protocol for a Prospective Clinical Registry and Proposal of Classification of Postoperative Complications	2015	E-CABG registry	Coronary artery bypass grafting	NS	Steering Committee	This is a European Multicenter Registry collecting prospective data on patients undergoing isolated CABG (E-CABG). The paper gives a summary of baseline, operative and postoperative variables	NS	Nil funding	Units of measurements are likely to differ between centers. In order to avoid any problem during data merging and analysis, laboratory data will be collected according to the suggested units of measurement	Baseline characteristics, heart rate, blood pressure, drug treatment, mobility, co-morbidities, risk scores, previous cardiac procedures, indication, antibiotics, procedural information, operative and anesthesiological methods, postoperative outcome, mortality, complications, further surgery needed, hospital length of stay, ITU length of stay	Prospective data collection, consecutive cases are recorded in a specifically created Access-datasheet with pre-defined variables. Each Steering Committee Member is in charge for checking the quality and validity of her/his institution's dataset. Auditing of the dataset will be performed every six months at institutional level by checking the data of 10 % of patients. Data without any patient identification code will be submitted to the principal investigator for further data checking and merging. The merged and checked dataset will be available to all E-CABG investigators for subanalyses. Follow-up data will be collected during January of each year for ten years. Each Steering Committee Member is in charge for checking the quality and validity of her/his institution's dataset. Auditing of the dataset will be performed every six months at institutional level by checking the data of 10 % of patients	Allow all contributers eligible for authorship of manuscripts.	NS	The research findings originating from data of the E-CABG registry will be disseminated in the scientific community by presenting the results of these studies in international congresses and publishing them in peer-review international journals in the fields of cardiac surgery and cardiology.	NS	NS	Registries require less resources than RCT's and are not narrowly focused on specific subsets of patients, but rather provide data on general patient populations with limited exclusion criteria. Registries can provide data on long-term outcomes that exceed the study window of a trial	NS	Registry approved by the local Institutional Review Board or Hospital Chief according to national guidelines for approval of registry studies. Patients' informed consent is collected in institutions where it is mandatory. Data including patients' codes are stored in institutional network and secured by access code
42	Hussey K Siddiqui T Burton P Welch GH Stuart WP	Understanding administrative abdominal aortic aneurysm mortality data	2015	Scottish Morbidity Record	Elective surgery for abdominal aortic aneurysm (AAA)	NS	NS	Aim of paper: To ascertain the completeness and accuracy of national administrative data relating to AAA repair within a single health board	NS	NS	NS	Demographics, indications, dates of intervention, precise procedures, mortality	Data entered on a secure web-based data collection system	NS	NS	NS	NS	Need for considerable resources and the implication of using medical time to collect or verify data. Concerns remain about data quality and administrative coding – a process that is not subject to external audit. Giving clinicians complete responsibility for the data presented to the public may be a double-edged sword. Randomised controlled trials are designed to make careful note of patient exclusions and have pre-defined structured follow-up protocols. Self-reported data might lack such vigilant oversight - can have "gaming of outcomes". Sources of errors include: transcription errors particulary relating the binary numbers, common misunderstandings and misclassifications of a clinical diagnosis or procedure. These errors could be reduced if coding is performed by appropriately experienced medical staff writing discharge summaries. However,	Capacity planning, commissioning services, and, ultimately, remuneration. Identify variation in process and outcome. Directly measure clinical performance at hospital and clinician levels	Clinican engagement in data gathering and governance are essential	Permission to collate, store, and examine patient identifiable data was obtained from the Caldicott Guardian. The Community Health Index (CHI) number (a unique patient identifier used throughout Scotland derived from the patients date of birth) was used to access electronic patient health records

																a reliance on the discharge process may itself be a weakness as there is an inevitable error rate within these documents. There is a risk of reporting bias and gaming when clinicians report their own outcomes - for example, adverse events become 'missing data'. To reduce this risk a possible solution is to have a unique patient identifier that follows the patient throughout the healthcare pathway so no events are missed. Data should be collected from a clearly defined point of care eg point of intervention - This single approach will help attain accurate clinical and administrative performance			
43	Briggs V Wilkie M	Chapter 14 Comparative audit of peritoneal dialysis catheter placement in England, Northern Ireland and Wales in 2011: a summary of progress to July 2012	2012	Audit of Peritoneal Dialysis Catheter Placement in England, Northern Ireland and Wales	PD Dialysis Catheter placement	York and Humber Renal Network and UK Renal Registry	York and Humber Renal Network and UK Renal Registry	The ultimate aim of the project is to develop an effective national PD access audit which will identify what represents an 'appropriate standard' of PD catheter function	A 2009 Renal Association working party recommended that the UK Renal Registry should collect centre specific information on various PD access outcome measures including catheter functional- ity and post-insertion complication	HQUIP	The principal data fields have been refined following a pilot audit of six centres in Y & H and discussed extensively through the Y & H PD audit group and the Dialysis Study Group of the UK Renal Registry	Demographics, date of first dialysis, date of surgical assessment , peritoneal dialysis catheter insertion procedure details, diabetes status, complications	The brief permitted a spreadsheet based data collection process for the first year, with subsequent data collection through the Renal Registry's electronic processes.	It was realised that there was a need to minimise the data to strengthen data completeness including clinically relevant data and objective reproducible measures	Forty three data collection spreadsheets were returned from a total of 63 centres describing 863 PD catheter placements of which 225 had a missing date of insertion	Electronic reports via the Renal registry website.	Patient and public partnership were engaged at several levels including as part of the audit steering group and UK Renal Registry Committee.	Data completeness	NS	NS	Data protection and patient confidentiality held within the UK Renal Registry
44	Mitchell D Lees T	The benefits of comparative audit in vascular surgery.	2011	This is a commentary on the benefits of comparative audit in Vascular Surgery	Vascular Surgery	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	There is evidence from examination of national statistics that registry data contains bias due to under-reporting of adverse outcomes. The majority of national audits are collected by clinicians on a voluntary basis. This lends itself to bias	The 2008 Vascunet report showed that the UK was an outlier with excess mortality (7.8%) following open surgical repair of abdominal aortic aneurysm. The effect was immediate, with expressions of disbelief from UK vascular surgeons. This was despite other publications showing similar mortality rates around that time. Had this international comparison not been done the UK vascular surgeons may well not have picked up on this being a problem. The consequence of this knowledge was the development of a quality improvement framework (QIF) by the Vascular Society of Great Britain & Ireland (VSGBI) setting a target to reduce	NS	NS

																		mortality to 3.5% by 2013. Since this time, mortiality rates have improved. Vascunet and the Vascular Society believe that international comparative audit has been good for UK vascular surgeons. It has dispelled fixed attitudes about the quality of care we provide, and we are beginning to show improvement. This will have benefits for our patients, not just in terms of outcome, but also in the change to our processes, increasing patient communication and ensuring that patients' are brought to optimal fitness prior to intervention		
45	Mason R. Foley N. Branley H. Maher T. Hetzel M. Adamali H. Suntharalingam J.	Pulmonary Langerhans' cell histiocytosis (PLCH): A new UK register	2012	National Pulmonary Langerhans cell histiocytosis (PLCH) Register	Management of PLCH including surgery	NS	NS	This is a research letter decribing the registry. The aim of the registry was to characterise the UK population sufferring from PLCH and to enable future research	NS	NS	NS	Demographics, symptoms, smoking history, lung function, surgical biopsy results, treatment including lung transplant	Demographic and clinical data were collected by post, from individual patients, their respiratory clinicians and their general practitioners.	Advertisements in the eBritish Thoracic Society (BTS) bulletin, at BTS meetings, the BTS BOLD conference and by contacting all UK interstitial lung disease leads	One hundred and six patients (17 deceased, 8 lost to follow-up) were initially identified from 53 centres	NS	NS	Patients joined the register voluntarily, potentially introducing selection and referral bias. Missing data from deceased patients or those lost to follow-up may also have introduced survivorship and selection bias	NS	NS	Consent taken from all patients that gave data
46	Elson D.W. Dawson M. Wilson C. Risebury M. Wilson A.	The UK Knee Osteotomy Registry (UKKOR)	2015	The UK Knee Osteotomy Registry (UKKOR)	Knee Osteotomy	NS	Steering committee	Aim of the registry is to improve the quality of patient care by monitoring outcomes. Specific goals: Define patient selection criteria, identify the devices and surgical techniques which give the best results	Electronic/web-based regstries have a distinct advantage in terms of staffing requirements and costs of paper based registries. UKKOR has been established by surgeons, independent of government agencies. Amplitude data platform (hosted by Bluespier) has been selected. The steering group deliberately approached several industry stakeholders in order to maintain a neutral bias towards any one company or commercial party.	Funding received from five companies with a stake in osteotomy surgery. Sponsoring companies will have access to performance data on their own products but not their competitors. In addition BASK have been supportive of the project and provided a generous priming grant	The inclusion of patient reported outcome measures is vital to increase any registries' sensitivity to define success. UKKOR has chosen to follow the same model employed by the NLR committee.	Demographics, patient co-morbidities , oxford knee score (OKS), the knee injury and osteoarthritis outcome score (KOOS), EuroQol (EQ5D) Activity participation questionnaire (OKS-APQ) from the Oxford group	NS	Clinicians can recognise that the registry will be useful as a governance instrument providing information for appraisal and revalidation. To increase compliance from both patients and clinicians, the registry has a visually appealing website which is informative and engaging with the inclusion of video explanations. All future publications drawing conclusions from UKKOR data will be authored by the "UKKOR research collaborative." Thus all surgeons who contribute patients and data will be listed as	NS	NS	Patients will be persuaded to participate because they can see their charted progress after surgery. Patients tend to have email address and phone number and this information is critical to facilitate automated patient follow-up.	Compliance from both patients and surgeons is a potential concern	Clinical registries use observational study methods from a broad population base and so their findings have strong external validity. The larger sample size from a registry database allows analysis of the multiple variables which can influence outcome. In addition, a prospective collection of complications (perceived by both patient as well as surgeon) offers transparency which should enlighten the consent process and improve patient understanding	NS	NS

													contributing authors on future PubMed citable manuscripts							
47	Van Gijn W. Wouters M.W.J.M. Peeters K.C.M.J. Van De Velde C.J.H.	Nationwide outcome registrations to improve quality of care in rectal surgery. An initiative of the European Society of Surgical Oncology	2009	This papers provides an overview of a number of european audits. We have collected data on UK audit(s) only: National Bowel Cancer Audit Programme (NBOCAP)	Colorectal cancer treatment including surgery.	NS	The Association of Coloproctology of Great Britain and Ireland (ACPGBI)	This paper provides an overview of the current European audit initiatives on rectal cancer and reflect on data- collection, outcome analysis and the results reported in the literature. We have collected data on UK audits only and general lessons learnt. The NBOCAP aims to improve outcomes from bowel cancer in the UK by promoting a careful and comprehensive collection of information on all patients who suffer from colorectal cancer	NS	NS	NS	Length of stay, mortality	Feedback to participating hospitals should become an important feature to improve quality of care. An important condition for the success of outcome registries is the quality of the collected data. Data have to be prospective, complete, case-mix adjusted and preferably collected by independent investigators. In addition, the quality of the data has to be assured by a second independent registry	NS	17% of all Trusts in England and Wales submitted complete data in 2007. There is not yet enough coverage to allow solid feedback. However, it is enough to create risk-adjusted models required to give a fair comparative feedback in the future	Annual reports	NS	NS	The existence of an audit improves performance (Hawthorne effect). The feedback of reliable data on individual performance of hospitals and/or surgeons catalysts quality improvements. Apart from a professional impetus to improve quality of care, there is a public demand for health care providers to justify the costs as well as the quality of the health care they deliver - Registries help provide this information	A high level of confidence in the validity of the data among the participants, is one of the most important factors determining the success of a surgical audit	NS
48	NELA Project Team	National Emergency Laparotomy Audit (NELA) Protocol	2014	NELA. This paper discussed the protocol for NELA	Emergency laparotomy	Royal College of Anaesthetists, the Clinical Effectiveness Unit of the Royal College of Surgeons of England and the Intensive Care National Audit & Research Centre	Royal college of anaethetists. NELA will be delivered by a central Project Team from the National Institute of Academic Anaesthesia's Health Services Research Centre based at the RCoA. Formal oversight will be provided by a Project Board consisting of key stakeholders. Scientific input will be provided by a Clinical Reference Group consisting of representatives from all relevant clinical professional and speciality stakeholders (including patient groups). The Project Board members are the decision makers and responsible for the commitment of resources to the project, such as personnel, funding and equipment. The Project Board	To enable the improvement of the quality of care for patients undergoing emergency laparotomy through the provision of high quality comparative data from all providers of emergency laparotomy	Online Web tool. In Year 1 an Organisational Audit was performed, with individual patient data collection in Years 2 and 3. NELA data will be linked to other sources of routine data including Critical Care Data (Intensive Care National Audit and Research Centre (ICNARC) case mix programme), Bowel Cancer Data (National Bowel Cancer Audit/Upper Gastro- intestinal Cancer Audit) and Hospital Episode Statistics (mortality data). The NELA has a Clinical reference group (CRG). The CRG is made up of relevant clinical professionals and speciality stakeholders and has direct input into the design and conduct of the audit. Senior representative(s) from the CRG sit on the Project Board as Senior User(s). The CRG consists of representatives from partner organisations as well as other stakeholders including patients. The CRG acts in an advisory capacity to the Project Team,	Funding from HQIP. NELA was one of the top two national clinical audits prioritised for immediate funding, in response to HQIP's call for new national audit topic proposals in 2011. It was commissioned following evidence of a high incidence of death, and a wide variation in the provision of care and mortality, for patients undergoing emergency laparotomy in hospitals across England and Wales. Funded for 3 years with the potential of a further 2 year extension	During the course of the audit, the team will explore the potential for patient reported outcome measures to be included in the Programme when appropriate.	Patient demographics, mortality, length of stay, time of admission, type of operation, time when consultant surgeon reviewed patient, time of operation, time of antibiotics, input by consultant during the operation, seniority of individual performing operation, seniority of CT scan reporting, time to access of theatres, operative urgency, critical care admission post op	Each NELA participant taking part is given a login, which enables the user to access and contribute data. The NELA Project Team is made up of methodologists, statisticians, Quality Improvement specialists and clinical fellows who will be analysing the patient data. The data will be analysed alongside the surgical and anaesthetic standards currently in place so as to see how many of them are being met and in what percentage of participating sites. The Project Team will also be linking Year 1 data with figures from the Office of National Statistics (ONS) and Hospital Episode Statistics (HES). By doing so they will be able to examine how many patients who underwent emergency laparotomy and were included in the audit were readmitted to hospital at a later date and how many of the patient died	Increase engagement by enabling participating sites to constantly review and analyse their hospital's results and improve the quality of patient care. Paritcipating centres can use the web tool's Export function and transfer their patient results onto an excel spreadsheet. The Project Team is in the process of developing a QI 'dashboard' for the NELA online web tool. The dashboard will feed back patient information to users in real time allowing them to examine the demographics of patients undergoing emergency laparotomy at their site while also looking at how often key surgical QI targets are being met. In October 2014 the Project Team published the Organisational Audit Action Plan, a form which provides a plan to assist sites in ensuring they are meeting the recommendations laid out in the	The first year of the Patient Audit saw over 20,500 patient cases entered with 100% of the 191 of the participating hospitals contributing patient data	Publication of reports on website - avilable to public. Reports sent to participating trusts chief executives shortly before publication and other stakeholders. Report findings communicated at regional and national conferences.	Patient act a stakeholders and formed part of the CRG which was tasked with audit development and running. While NELA does not require a patient's consent to be included in the audit, it is important to the Project Team that patients are aware of their inclusion in NELA and that it works closely with patient liaison groups. For this reason a patient representative is present on both the Project Board and the Clinical Reference Group and the audit's website features a page designed to educate patients on what NELA is and how the audit is being conducted. The NELA website has a section of FAQ's for frequent questions asked by patients	NS	NELA enables participants to examine their hospitals' results while also seeing how they compare to the audit-wide average formed by the rest of their fellow participants. Enables secondary care providers to improve the delivery of care to patients undergoing emergency laparotomy using information produced by the audit. Facilitates the development of effective change (quality improvement) initiatives and thereby spread examples of best practice.	NS	Due to the fact that patient indefinable information (such as patient name, DOB, NHS number, etc.) is visible on the web tool a new user requires a trust or NHS email address in order to be registered. Additionally, the web tool has been designed so as to not allow members of the Project Team access to sensitive information when logged in, with all patient identifiable data having been anonymised

	oversees strategic direction and is responsible for monitoring all aspects of delivery of the project , and is accountable to the stakeholder organisations. The Project Board meets 6-monthly and receives direct reports on the delivery of the project from members of the Project Team leaders (Chair, Clinical Lead and Methodologist) as well as minutes from the Clinical Reference Group. The Executive is ultimately accountable for the project, supported by the Senior User and Senior Supplier (HQIP) - Senior Supplier (responsible for providing the goods or services) - will be ultimately accountable for delivery of the project. The Senior User (responsible for defining what is required from the project) - commits user resources to the project. The NELA Project Team is responsible for the ongoing delivery of the Project. Project Chair - Overall responsibility for delivery of the project. Clinical Lead - Responsible for liaison with the Clinical Reference Group members, liaison with NHS emergency laparotomy network, providing clinical advice during analysis, dissemination of audit results and working on quality improvement initiatives. Project Manager - Responsible for day to day management of the project	providing speciality specific advice, and lay advice as appropriate. The CRG reviews the audit design regularly and also reviews drafts of any reports and recommendations issued. CRG consisted of: Trsu management representative, RCS, royal college of radiologists, Royal College of nursing, royal college of anaesthetists, quality observatiroes, patient representatives from anaesthetia, surgery and the elderly, NHS emergency laparotomy network, Intensive care society, British geriatric society, ASGBI, AAGBI, assoication of peroperative practice, age anaesthesia association.	within 30 or 60 days of their initial procedure.	NELA Organisational Report and if not, what actions need to be taken to achieve these aims

National Hip Fracture Registry 2015, annual report	National Hip Fracture Registry 2015, annual report and NHFD Preliminary National Report 2009	2015, 2009	NHFD	Hip fractures	Royal College of Physicians (RCP), British Orthopaedic Association, British Geriatrics Society, RCS, Age UK, National Osteoporosis Society, Falls and Fractures Alliance, HQUIP	NHFD is run by an Executive representing the core clinical specialties, and also includes representation from a patient group. A larger and more broadly- based Steering Group provides advice; and a smaller Implementation Group, deals with project development, data analysis, and the generation of reports. A data set subgroup is responsible for the monitoring and further development of the NHFD standard data set. The NHFD is managed by the Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians (RCP) as part of the Falls and Fragility Fracture Audit Programme (FFFAP) alongside the Fracture Liaison Service Database (FLS-DB) and Falls Pathway workstream	To improve the delivery of care for patients having falls or sustaining fractures through effective measurement against standards and feedback to provider	The National Hip Fracture Database was set up as a collaborative venture by the British Orthopaedic Association and the British Geriatrics Society in 2007. Work towards the establishment of NHFD started in 2004, with a series of meetings by clinicians mainly from the British Orthopaedic Association and the British Geriatrics Society. These team members examined the experience of existing hip fracture audits with a view to building a preliminary national database and establishing a nationally agreed dataset. By 2007 – with the support of the NHS Information Centre, and learning from the highly successful Myocardial Infarction National Audit Project (MINAP) – NHFD was able to provide participating trauma services with a comprehensive national audit that could help them monitor and improve their care. In parallel was the development of the Blue Book - a multi-disciplinary authorship group that included anaesthetic, orthogeriatric, general practice, nursing, orthopaedic and pharmacological expertise that reviewed the current evidence on fragility fracture care and produced a concise and practical 75-page handbook. Crown Informatics is the web provider and this has enabled the development of a more interactive, user-friendly website. Website is continuously being upgraded to provide graphical 'real-time' information to support the monthly clinical governance meetings.	The development of NHFD since 2004 has depended upon the support of the British Orthopaedic Association (BOA), the British Geriatrics Society (BGS) and other relevant professional groups; and on generous funding from the Association of the British Pharmaceutical Industry (ABPI) and Association of British Healthcare Industries (ABHI), the professional bodies of the pharmaceutical and devices industries respectively. A substantial grant was obtained from the Department of Health. Total income for 2007/2008 was £519,605 with a total expenditure for the same period of £458,188. Following the set up of the regstry, ongoing funding has been from HQUIP. The cost of reliable data collection is estimated at around £50-60 per case - this cost should be seen in relation to the overall cost of hip fracture care.	Data was collected to allow easy comparison to NICE recommendations.	Patient demographics, place of residence, ASA, length of stay, admission via A&E, length of NHS care following hip facture (including care in the community), whether fracture occurred when patient was an inpatient, type of surgery, type of implant, type of fracture, re-operation, pressure ulcers, mortality, time to an orthopaedic ward, time to surgery, type of anaesthetic, complications, morbidity, perioperative medical assessment, AMTS documentation, received falls assessment, mobilised out of bed 1 day post op, received bone health assessment, whether the record has met all criteria for best practice tariff	Many hospitals participating in the NHFD do not actively follow up their patients after discharge, so to calculate 30-day mortality NHFD relies on obtaining validated, third-party mortality data from the Office for National Statistics (ONS). They then use a casemix-adjustment model to ensure that reported mortality figures are appropriate to the demographics of the local patient population. LOS is analysed with an annualised line that smooths out seasonal variation. The registry has a Best Practice Tariff run chart that allows hospitals to see what proportion of their patients are receiving key elements of best clinical care and overall BPT attainment. The NHFD only excludes patients from analyses that prove impossible due to specific deficiencies in their dataset, but still include them in any other analyses for which relevant dataset fields are complete. Data quality issues can be addressed by well-funded data collection, and by the use of data quality checking mechanisms	Use of web-based technology facilitates information transfer, data handling, analysis and feedback; and advice and user support. Regular feedback to participating units helps maintain interest and increase participation in the registry. During the NHFD launch, advertisment via press coverage, presentations at relevant national meetings, and word of mouth ensured that the rate of participation was rapid. NHFD has established online graphs that provide individual hospital teams with live data on performance, time to theatre, mortality, length of stay (LOS), best practice and patient safety. Such charts are key to monthly clinical governance for hip fracture programmes and are therefore very useful for clinicians and hospitals. Easy to use website. NHFD provides user support and has a downloadable toolkit. Published reports are a useful method of increasing 'buy-in' – they provide a permanent record of progress, and can serve to raise the profile of NHFD and bring it to the notice of non-participating units, commissioners of hip fracture care, relevant professional bodies, and strategic health authorities.NHFD will enable the collection of data required to enable the commissioning of services	When the registry first started, there were concerns about both the completeness and the quality of data. This has been addressed over the years of the registry and currently all 180 eligible hospitals in England, Wales and Northern Ireland are now regularly uploading data.	Annual reports, research and quality improvement projects. The NHFD website provides summary data for local teams to use eg admission numbers, time to an orthopaedic ward, time to surgery, casemix, performance against NICE standards - these are set against reference lines derived from national average figures. NHFD has since 2015's report been using colour coding and grading on their tables to allow readers to ascertain how their hospital is performing and in which quartile their practice lies when compared with national performance. Benchmarking comparisons between hospitals are difficult, as different trauma units have very differing hospitals in their catchment area. For this reason NHFD has developed a run chart that allows individual hospitals to benchmark their performance against their own previous figures, and to monitor the effectiveness of local initiatives to avoid inpatient falls.	Website charts will be made to the public as part of NHFD's commitment to the transparency of audit data	Continuous and comprehensive data capture is challenging, and hard to achieve using already busy clinical staff with inevitably conflicting priorities. In particular, rigorous documentation of time of arrival and follow-up at 30 and 120 days is challenging. In 2015 there was poor reporting of pressure ulcers (4/180: 2%) and no reoperations (47/180: 26%), suggesting that hospitals have no mechanism to monitor these patient safety concerns. In earlier registry reports, they identfied concerns about data completion and inaccuracies of data included (eg fracture type, nature of surgery, follow up. This has improved over time.	Between 2007 (start of registry) and 2011 rates of early surgery increased from 54.5% to 71.3% nationally, having been stable previously. Thirty-day mortality fell from 10.9% to 8.5%, compared with a smaller reduction from 11.5% to 10.9% before 2007. Annual relative reduction in adjusted 30-day mortality was just 1.8% from 2003 to 2007, but 7.6% over 2007–11 (p<0.001). The study results suggest that by 2011 around 1,000 fewer people a year died within 30 days of hospital admission for hip fracture than would be expected had pre-2007 time trends continued as before. Some of this additional improvement could be due to other policies, as well as the introduction of the NHFD. The NHFD occupies an increasingly central position in supporting other agencies to monitor and evaluate the quality of healthcare delivered to frail older people. These agencies include (CQC, Monitor, CCGs, NICE). Registry enables paticipating centres to learn from theirs and others experiencies and improve care	Prompt and reliable feedback to participating units is an essential feature of successful audit	Personal confidential data items for this audit were processed by Crown Informatics under section 251 (of the NHS Act 2006) approval, prior to anonymisation. Data are anonymised and securely transferred to the Royal College of Surgeons of England for analysis. Data were collected and processed with specific approval of the secretary of state for health on the recommendation of the Health Research Authority (HRA) Confidentiality Advisory Group (CAG) under the Health Service (Control of Patient Information) Regulations 2002. This is more commonly referred to as section 251 approval, and references to 'section 251 support or approval' actually refer to approval given under the authority of these regulations. Secure access for staff involved in the treatment of patients with hip fracture to the NHFD database is requested by the NHFD lead clinician for each organisation that uploads data. Once the request is validated, secure access is provided by the NHFD administration team to facilitate data entry to the audit. The data are entered via a secure website, and access to this is via a secure login name and password

50	Clinical Effectiveness Unit, The Royal College of Surgeons of England	National Vascular Registry: 2015 Annual report. London: The Royal College of Surgeons of England	2015	National vascular registry	Emergency or elective procedures for the following patient groups: Peripheral arterial disease, AAA repair, CEA or carotid stenting	National Vascular Database (NVD), the Carotid Interventions Audit, VSGBI Audit Committee	The NVR is assisted by the Audit and Quality Improvement Committee of the Vascular Society and overseen by a Project Board, which has senior representatives from the participating organisations and the commissioning organisation	Aim of the registry : To provide comparative information on the performance of NHS vascular units and support local quality improvement as well as inform patients about major vascular interventions delivered in the NHS. Airm of the 2015 report: To give an overall picture of the care provided by NHS vascular units	Web-based system. The registry was created from an amalgamation of the National Vascular Database (NVD) and the Carotid Interventions Audit. A new IT system was developed in collaboration with Northgate Information Systems in 2014.The most notable changes were to the datasets for the four procedures in the old NVD and the addition of a new dataset for lower- limb angioplasty / stent procedures. These changes were based on advice from vascular specialists on ways to simplify how data were recorded, and to ensure the datasets reflect changes in clinical practice. As a result, the NVR datasets for each procedure are now smaller and the recording of patient characteristics is more consistent across the procedures. A further improvement is that the records for patients who have one operation and later come back for another are now linked. As this is a procedure based regustry, it was decided to focus mainly on outcomes rather than the process of care. The registry took on-board comments from users to develop the data items.	Funding by HQUIP as part of the National Clinical Audit Programme (NCA). HQIP holds the contract to manage and develop the NCA Programme	The amputation dataset was adapted to capture key issues highlighted by the 2014 National Confidential Enquiry into Patient Outcomes and Deaths (NCEPOD) review of lower limb amputation.	Demographics, procedure, time to surgery (emergency and elective), formal anaesthetic review, fitness measurement, pre-operative imaging, whether patient discussed at MDT meeting, procedure, mortality, complications, further unplanned intervention	NS	NHS hospitals in England and Wales are required to report on their participation in the Vascular Registry as part of their Quality Account. Several online reports were introduced to support data entry. The registry team developed an online report designed to support consultant revalidation. THe NVR used an IT system that has evolved following consultation with users and vasular specialists. This evolution and improvement in systems has improved data completeness. For example, some of the characteristics used for risk adjustment were typically entered for between 80-85% of patients. Variables used for risk-adjustment are now mandated which has resulted in 100% completeness for these characteristics from January 2014. When the NVR updated it's dataset, following advice from vascular specialists, they were advised to simplify how data were recorded, and to ensure the datasets reflect changes in clinical practice	2871 endovascular and 5387 bypass procedures (For peripheral vascular disease) performed in the 2014 calendar year - corresponds to an estimated case-ascertainment of 15% and 90%, respectively. Likely that the cohort of patients captured by the NVR in 2014 for were less sick than all patients having a major lower limb amputation - this could explain the lower than expected mortality rate obtained by the NVR for lower limb amputation. From routine hospital data, estimated that there were approximately 2300 below knee and 2500 above knee amputations performed in UK hospitals for peripheral arterial disease during 2014 - vascular units submitted 1200 of the former and 1265 of the latter, giving an estimated case-ascertainment of approximately 50% for both procedures. There is high case attainment for data collected by NVR for elective AAA repair and CEA. However need improvements in cas attainment for lower limb procedures	Annual reports. Reports contain options that allow the results to be tailored to the user's requirements.	NS	In some cases incomplete data on MDT assessment and date of imagaing. Data submission rates for lower limb revascularisation need to improve if the NVR is going to reach its full potential in supporting us to make these improvements	The data from NVR is particularly useful when undertaking local reviews of vascular services and commissioning groups are increasingly like to rely on this information. Helpful when comparing services nationally.	NS	NS
51	NJR Editorial Board	NJR 12th Annual Report	2015	National Joint Registry	Hip, knee, ankle, elbow, shoulder replacement surgery	British Orthopaedic Association (BOA), Medical Advisory Committee (through which specialist orthopaedic societies are formally represented). International Society of Arthroplasty Registers. The NJR works with many stakeholders including patients, regulators, hospitals, industry, individual	The NJR is managed by the Healthcare Quality Improvement Partnership (HQIP) under a contract with NHS England as part of the delivery of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP supports the work of the NJR Steering Committee and all its sub-committees. The NJR Steering	To collect information on all hip, knee, ankle, elbow and shoulder replacement operations, to monitor the performance of joint replacement implants and the effectiveness of different types of surgery, improving clinical standards and benefiting patients, clinicians and the orthopaedic sector as a whole. Cover England, Wales, Northern Ireland and will be	Developed by Department of Health and Welsh Government in 2002.	The NJR is funded through a levy raised on hip, knee, ankle, elbow and shoulder procedures. Up until 31 March 2014, the NJR levy payment on hip, knee, ankle, elbow and shoulder implants was collected from purchasing hospitals by orthopaedic device manufacturers Manufacturers processed the	The majority of the data can be collected via tick boxes, some information is required in white space format. In terms of collecting PROMS - There is interest in how patient reported outcomes of joint surgery change in the longer term and whether the outcomes of surgery are best evaluated at six months after surgery or at a later point.	Patient consent, demographics, operation date, ASA grade, anaesthetic type, operation funding, consultant in charge, operating surgeon grade and name, first assitant grade, side of operation, BMI, indications, procedure, patient position, surgical approach, comorbidities, living arrangements, thromboprophylaxis regime at time of operation, untoward intraoperative events, primary or secondary procedure, indication for revision cases, type of implant and	Data input by surgeons. Data can be entered electronically directly into the NJR database. Printed forms are also available. Currently, all patients treated by or on behalf of NHS England for an elective knee and/or hip joint replacement are invited to complete a PROMs questionnaire prior to surgery and again at six months after surgery. Data cleaning is carried out eg	Any provider carrying out hip, knee, ankle, elbow or shoulder surgery is now mandated to submit 100% of eligible primary and revision procedures to the NJR (including the private sector). NJR has a supporting Data Quality Strategy. This includes a programme of work in partnership with hospitals to encourage greater compliance. The NJR helps	Complaince in data submission was 96.6%. Consent was obtained in 91.8% of cases and linkabilty was possible in 95.15 of cases. CNJR has a Supporting Data Quality Strategy. This strategy outlines the registry's current and future intentions for ensuring data quality. Crucially, this	Has online annual report website 'NJR reports'Digital annual reporting arrangements and new interactive clinical activity reports. Also has annual reports. There is also publication on outcomes of individual surgeons. Specific website for patients, providing information about hospital. The reporting website has historical data,	Drive towards patient engagement in the registry and bringing the patient voice to the heart of NJRSC decision making. Patients will be able to see individual hospital performance and compliance in terms of submitting data through the NJR data publication and NHS Choices	Sufficient resources for the registry. 11% of records have been excluded because there were insufficient patient details to enable linkage. Cases from Northern Ireland were excluded because there was no tracing service for them. Person-level identifier was available for 96% of operations since the beginning of 2008, but in earlier years the proportion had been much lower - therefore long-term follow up data may not be as representative as short-term follow up data. In 4.4% of cases of revision surgery, there was no	The registry supports transparency by using and sharing relevant hospital, surgeon and implant-pricing data, as well as enabling the linkage of NJR data with other expanding healthcare information, and helps tackle issues and problems in joint replacement surgery. The registry helps surgeons choose the	NS	Must have patient consent prior to collection of data. Patient consent (to record their details in the NJR) was recorded as 93.8%. o avoid sending paper records through the post and to ensure maximum protection to the data, the NJR uses an electronic system for collecting the data. This includes a secure link for

surgeons and procurement. Important to form international collaborations - to help ensure that the registry has the ability to harmonise with global orthopaedic device initiatives	Committee is an NHS England Committee of experts. There are industry representatives on the steering committee. The committee is responsible for overseeing the strategic direction of the NJR. Also have sub-committees, Implant Performance Sub-committee, Surgeon Outlier Sub-committee. There is also a NJR management team that supports the work of the Steering Committee. Regional clinical coordinators (RCCs) and regional coordinators (RCs) work in partnership to ensure that hospitals are supported in their understanding of the requirements of the NJR. The NJR Centre has been set up to manage the development and running of the NJR database for all data collection and to help share NJR information with clinicians, patients and other stakeholders	expanding to the Isle of Man	levy on behalf of the NJR and then made the payment to the registry. In return for their role in administering the levy, manufacturers charge a supplier administration fee which was included in the calculation of the levy. The cost per joint was £20.00 (inc administrative fee). From April 2014, the cost of the NJR levy is a new, lower rate of £15.60 per procedure where each provider organisation is issued with an annual invoice directly from the Healthcare Quality Improvement Partnership (HQIP) for an NJR subscription charge based upon the provider's prior year's procedure volume. Orthopaedic device manufacturers contributed towards the NJR Management Feedback system which supports post-market implant surveillance	brand, morbidity, mortality, pre and post operative PROMS (PROMS included Oxford Knee scores, EQ-5D, PROMS at 6 months post op, 1 and 3 years after their primary procedure), hospital submitting data, time to follow up, implant survivorship, white space surgeon notes	removing duplicates. Patient consent and a valid NHS number allows the NJR to link a patient's primary and revision operation together, giving a picture of implant survivorship by implant type and brand. Documentation of implant survivorship and mortality requires a person-level identifier to be able to relate primary and revision operations on the same individual. I	increase participation through a national programme of local audits to assess data completeness and quality. These audits work to identify where data might be missing to improve the general quality of their data in the registry. Those actively taking part in the audit and achieving best practice and quality will gain the new NJR Quality Data Provider certification. Renewable annually, this award is designed to recognise quality data provision and the commitment to patient safety through compliance. The certification will also highlight those hospitals who do not comply with mandatory NJR requirements, communicating this status through the NJR data publication and NHS Choices websites, thus allowing patients to be aware of hospitals that choose not to meet NJR quality standards. When organisation provide data to the NJR, the NJR shares information it has on best implant prices that can help trusts save costs - this implant price benchmarking service is called INFORM. The introduction of the Best Practice Tariff for hip replacements provides incentives for hospitals to report data to the NJR.	includes a programme of work in partnership with hospitals to encourage greater compliance; while data capture for the NJR is mandatory, many hospitals struggle to achieve it. The number of cases reported to the registry every year is now in excess of 200,000. 2014/15 had the highest ever annual number of submissions at 226,87. The total number of procedures recorded was 1.8 Million at March 2015. Patients who had elective primary knee replacement in 2010 were asked to complete pre and postoperative PROMS - of the 32,147 invited participants, 20,721 and 17,485 respectively responded at one and three years post op. Of a total of 1,837,781 NJR records, around 11% have been lost because no suitable person- level identifier was found - in around half of these 201,548 procedures (47.3%), the patient had declined to give consent for details to be held, the remainder being attributable to tracing and linkage difficulties. Linkability (the ability to link a patient's primary procedure to a revision procedure) was recorded as 92.8%	going back to 2005 in most cases. Using the dedicated website, readers can use interactive, filterable graphs to identify the key information and trends associated with reports for hip, knee, ankle, elbow and shoulder data. Able to see data on how many hospital are participating in the NJR. Data reporting includes mortality, rates of revision, reasons for revision, survivorship analysis. The steering committee faciliate the use of NJR data for research	websites. They have developed websites for patients that give information on how hospitals are performing. There are two patient representatives on the steering committee	primary operation for that patient recorded in the NJR. This would have been either because the primary had taken place at an earlier point in time (before the NJR data collection period began in 2003) or was not included for other reasons such as the operation being performed outside the geographical catchment area of the NJR or consent for data linkage not being provided at the time of the primary procedure. Some revision cases were excluded because they could not be matched to primary joint replacements.	best implants for patients. It empower patients by helping them find out more about the implants available. The registry improves patient safety by showing how well implants, surgeons and hospitals perform and take action where it is needed. It gives hospitals, surgeons and implant manufacturers feedback about their performance to help them improve patient care. It helps surgeons quickly decide whether patients need to return to hospital if implant problems are found	transferring the data from the hospital to the central database. All the data held on the central database is encrypted to provide further protection. Patients' personal data is treated as confidential at all times and cannot be used outside of the NJR. This data is only available to the patient that it relates to and their surgeon. The steering committee faciliates the use of NJR data for research. Data collected via the NJR may be used for medical research but only if it has passed ethical review and if the outcomes are expected to provide significant benefits to the healthcare of patients. However, any data provided will be anonymised so that it is not possible to identify individuals. In accordance with the Data Protection act (1998), patients can request a copy of the personal information that the NR holds about them at any time

52	David Chadwick, Robert Kinsman, Peter Walton	The British Association of Endocrine and Thyroid Surgeons 4th National Audit Report	2012	UK Registry of Endocrine and Thyroid Surgery (UKRETS)	Endocrine Surgery	National Cancer Intelligence Network	BAETS and Dendrite manage the registry	To ensure high quality surgical care	Dendrite build, maintain and host the regisry. They also provide the data analysis and publish the reports.	Sponsorship by Covidien since 2011 and ongoing. Ethicon Endo-Surgery provided the initial start up funds	It is important to have a balance between collecting sufficient minimum data to provide worthwhile analysis, and the burden of over-collection	Demographics, indication for surgery, diagnosis, other diagnoses, site of lesion (left/right), date of operation, histology, use of fine needle aspiration, lenth of stay, complications, imaging, use of nerve monitor, use of harmonic scalpel, use of ligasure, pre-operative imaging, use of MDT, use of laryngoscopy, grade of surgeon, grade of assistant, consultant involvement, post operative vocal cord assessment, procedure information, type of approach (posterior, endoscopic, open, transperitoneal etc), energy source (bi/monopolar), re-operation, only patient comments and surgeon comments are in white space format	Electronic data collection. Dendrite involved in data analysis	Participating in the UKRETS is an obligatory requirement for BAETS Full Members. It is a requirement of HQIP that all thyroid operations are entered onto UKRETS as thyroid surgery has been chosen by the Chief Medical Officer to be one of 13 specialties where consultant level outcomes should be openly available for public viewing. The registry facilitates appraisal and revalidation process. Surgeons get personal results. Having mandatory fields will make it impossible to log off without completion. Making data submission compulsory for membership will also increase data completion. Other methods to improve data entry include: publishing of members' rates of complete data; Identification of those high-volume surgeons with high rates of complete data, with a view to sharing their methodology for successful and comprehensive data acquisition; prevent cases being logged until certain basic fields are complete	The report has outcomes of 29,000 surgical procedures. There was enormous variation between individual surgeons with respect to their rate of missing data. Some achieved well above average rates of data completeness, some at or close to 100% complete. Others, however, have high rates of incomplete entries, occasionally close to zero percent. The variation did not appear to be due to surgeon-volume, with many of the highest volume surgeons represented amongst the enthusiasts, despite the larger number of cases requiring data entry. Audit fatigue over time also does not appear to explain this divergence, as rates of incomplete data entry are stable over the last 5-6 years. However, data entry for outcomes at follow-up is less complete than for outcomes at discharge, reflecting the increased effort required to obtain these data and update the case entry	The results from the registry are published openly via the Surgeon Specific Outcomes Report for Endocrine Surgery. Access to data for research requires a formal application and peer review process. Dendrite are involved in publishing the registry the reports	NS	It is a purely a surgical database, so that data on for instance adjuvant therapies for thyroid cancer or for tumours not undergoing surgery are not collected. The majority of thyroidectomies in the United Kingdom are performed by non-BAETS members, and therefore are not recorded in our audit. There is considerable variation between members in completeness of data entry - this variation, and the level of missing data overall, has the potential to compromise assessment of surgical outcomes. There was considerable missing data for all endocrine case types. For thyroidectomy for examples, even the most basic data that would allow simple calculation of complication rates were missing in over 10% of cases on average. Other data fields have even higher proportions of incomplete data entry. This is similar to parathyroid and adrenal data entry	Facilitate appraisal and revalidation process, surgeons will get personal results	Success of a registry is dependant on it's members to submit data.	Access to UKRETS is granted on Full Membership of BAETS. Surgeons can then access the registry to enter details of all endocrine operations. Access to data for research requires a formal application and peer review process

53	National Bowel Cancer Audit Project Team	National Bowel Cancer Audit Report	2015	National Bowel Cancer Audit	Colon and rectal cancer.	Health & Social Care Information Centre, Association of Coloproctology of Great Britain and Ireland, and the Royal College of Surgeons, HQUIP	Leadership from the National Bowel Cancer Audit Project Board. The Health and Social Care Information Centre provides project management and technical infrastructure, while the ACPGBI provides clinical leadership and direction. The audit was carried out by the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England in partnership with the Association of Coloproctologists of Great Britain and Ireland (ACPGBI), and the Health and Social Care Information Centre (HSCIC)	To improve the quality of care and survival of patients with bowel cancer, and meets the requirements as set out in the NHS cancer plan, NICE guidelines and the report of the Bristol Royal Infirmary inquiry. To provide more information on the prevention, diagnosis, treatment and care of this disease and the outcomes. Audit's overall aim is to measure the quality of care and survival of patients with bowel cancer in England and Wales.	NS	Funding by the HQIP as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP)	Measures for cancer management were drawn from NICE and ASGBI. The dataset has been redesigned to contain fewer items, some of which are mandatory, with the aim of improving data completeness across all patients.	Demographics, date of diagnosis, organisation first seen, source of referral, major site of cancer, performance status, synchronous cancer, planned cancer treatment type, reason for no treatment, TNM category, ASA, monitoring, curability, surgical urgency, primary procedure, surgical access, immediate post operative care, status of excision margin, treatment modality (all have drop down lists)	All participating trusts submit their data via the Clinical Audit Platform. The Welsh data is submitted directly from the Cancer Network Information System Cymru to the Clinical Audit Platform. The analyses for the report was carried out by the Clinical Effectiveness Unit of the Royal College of Surgeons of England with support from the Health and Social Care Information Centre. The Audit dataset is linked to HES data at the patient level to obtain further information on patient care and follow-up, such as stoma reversal and emergency readmissions in England. HES is useful for analysing patient follow-up, such as emergency readmissions and stoma provision	The dataset has been redesigned to contain fewer items, some of which are mandatory, with the aim of improving data completeness across all patients	This audit includes data on over 30,000 patients diagnosed with bowel cancer between 1 April 2013 and 31 March 2014	Annual audit reports. The Audit publishes data at the individual surgeon level in terms of 90 day post-operative mortality for patients undergoing elective/scheduled major surgery after being diagnosed with bowel cancer. Also publish the number of procedures performed by each surgeon. The Audit data collection system has the facility to provide feedback to consultants and Trusts about the data they have submitted. Most results are descriptive and are presented in simple tables with percentages of patients in each group	NS	NS	NS	NS	Data protection and privacy is an important part of the Audit. No individual patient can be identified in the results
54	The Ear Foundation	The UK National Registry for Bone Conducting Hearing Implants	2015	The UK National Registry for Bone Conducting Hearing Implants (BCHI)	Bone Conduction Hearing Implant Registry	13 centres performing BCHI	Ear Foundation	To indentify the number of BCHI nationwide and eventually worldwide; to secure funding for BCHIs, to inform policy and practice, to help plan services.	NS	Supported by Oticon Medical and Cochlear Europe	NS	Demographics, unilateral/bilateral hearing loss, unilateral/bilateral fitting of BCHI, aetiology of hearing loss, Will include usage and indications for BCHI	Data is sent by the participating centre to The Ear Foundation.	NS	Number of users is 3104	Website report	NS	NS	Provides outcomes data and can provide evidence of clincial cost-effectiveness. It can help secure funding of BCHIs. It can help inform policy and practice	NS	All data are securely stored and kept confidential

Hazari A. Walton P.	The UK National Flap Registry (UKNFR): A National Database for all pedicled and free flaps in the UK.	2015	UK National Flap Registry (UKNFR)	Pedicled and free flap operations	British Association of Plastic Reconstructive and Aesthetic Surgeons (BAPRAS), British Association of Head and Neck Oncologists (BAHNO), British Association of Oral and Maxillofacial Surgeons (BAOMS) and Association of Breast Surgery (ABS). Supported by Prof Danny Keenan, Medical Director of HQIP and a practicing cardiac surgeon.	Managed by Dendrite	To collect information on all free and major pedicled flap reconstructions for the Head & Neck, Breast, Upper & Lower Limb, Perineum and Trunk carried out in the UK and through this, assess the quality of care we provide for patients.	The registry is multi-browser and will work on Safari, Google Chrome, Firefox. and Internet Explorer	NS	For PROMS questions, they ensured that the number of questions are short, which increases compliance from patients whilst having valid outcomes. Pre-operative/baseline Breast PROMS questionnaire is currently not in place as this requires a separate electronic setup and the first time a patient is placed in the registry is on the day of the operation, usually whilst writing the operation note. For Lower Limb reconstruction, the PROMS questionnaire is sent to the patient at 9 months. An effort has been made to keep UKNFR use simple as much as possible for surgeons so that it becomes an integral part of their record keeping	A free text box is available in the operation section for additional operation notes. Operative details. Length of stay. Postop chemo, postop radiotherapy, ITU admission (unplanned/ planned), date of discharge, and unplanned re-admission to hospital. Patient Reported Outcome Measures (PROMs) are being collected for Breast and Lower Limb Reconstructions	NS	There are time-triggered PROMs questionnaires being sent directly to the patient via an automated text/ email app and collated centrally, removing the human interface. Keep it as simple as possible for surgeons to use and keep it quick. The UKNFR notes that there is a learning curve speed to entering the data, and initially testers found the first few flaps data entry to take longer than 15 - 20 min. Once a user conducts a dozen cases or more then the system should become much more familiar only take you a few minutes. It is useful for surgeons - they can use the data for appraisal and revalidation. Outcomes, including PROMs, are high on the NHS agenda; revalidation, robust appraisal and transparency will make such data essential for an individual surgeon as well as for the hospital, and UKFNR will be a powerful resource to deliver this data. The registry is multi-browser and will work on Safari, Google Chrome, Firefox. and Internet Explorer - this makes it easier for the registry to be used. The registry can be accessed on an iPad in a secure and quick manner - the UKNFR is completely tablet device compatible. All incomplete data are highlighted by a yellow triangle and when this is clicked it takes you straight to the field that needs to be completed. The patient record list uses a 'traffic-light' system: an amber background colour indicates incomplete data, green is complete data and red, which is a rare event, will indicate that a patient has died perioperatively. An amber background colour will persist until mandatory fields are complete	NS	NS	Patient Reported Outcome Measures (PROMs) are being collected for Breast and Lower Limb Reconstructions, with time-triggered questionnaires being sent directly to the patient via an automated text/ email app and collated centrally, removing the human interface. For Breast surgery, three BreastQ Reconstructive modules: satisfaction with outcome, satisfaction with information and satisfaction with breast, will be sent directly to the patient at 6 and 12 months.	NS	The data can be used by surgeons for appraisal and revalidation as required by the General Medical Council. The registry will allow appropriate comparison of clinical performance with national and regional peers	NS	The registry requires the entry of patient confidential information. Once these are approved, it means that the user will not have to ask for consent from patients to enter personal confidential information into UKNFR, such as name, date of birth. Until these are granted, written consent must be taken from each patient. For collation at a national level, all personal information is anonymised so that patients cannot be identified. User must accept the Terms of Conditions and privacy policy when you first registered. UKNFR has a "secure" server, which automatically encrypts data traffic between the sever and the "client" computers

56	Connolly S.S. Rochester M.A.	Nephroureterectomy surgery in the UK in 2012: British Association of Urological Surgeons (BAUS) Registry data.	2015	BAUS Registry data for Nephroureterectomy surgery	Nephroureterectomy surgery	BAUS, Nuvola	BAUS	To respond to the government initiative for the compulsory reporting of surgeon-specific outcomes for surgery, the BAUS required urologists performing any nephrectomy surgery in England to enter their data for all such surgery. To provide an accurate description of current practice to facilitate audit of individual surgeon and centre outcomes	Data entry was invited from all urologists within the UK. Data were entered by each individual surgeon's team to a web-based database tool established by the BAUS Section of Oncology and commissioned from Nuvola	Funding from Nuvola	At the outset of this report it was noted that data were very limited in relation to tumour location, preoperative diagnostic evaluation and precise details of the MIS undertaken. It is hoped that this will be addressed in future modifications of the database. Data on long-term and oncological outcomes were also not adequate - it is hoped that these will become available in the future.	Basic demographic details; 59 patient-specific parameters were included	Registry data entered by each individual surgeon's team. Before any formal analysis, a process of 'data cleansing' was undertaken centrally by a BAUS committee to address inconsistencies between the listed surgery and the preoperative indication.	A few of the data items were mandatory, but there was no obligation to provide complete data. Collected data was under the following themes: (i) Presentation and indication; (ii) Diagnosis and co- morbidity; (iii) Stage of malignancy; (iv) Surgeon; (v) Details of procedure; (vi) Outcome and complications; and (vii) Histopathology.	Entry of data to the database was made available to all urologists within the UK. 6042 nephrectomy surgeries reported to BAUS in 2012. there is no requirement for urologists in England to have membership of BAUS, there is no other similar national organisation within the UK. It is thought that the data for nephrectomy surgery gathered by the BAUS encompasses >80% of all such surgery performed in the UK in 2012, representing a substantial strength of the present publication.	Annual Reports	NS	Some cases performed within the private healthcare system may have eluded reporting in this dataset, but there is no reasonable evidence to suggest that this introduced significant bias.	The registry offers considerable insight into current practice patterns surrounding NU surgery within the UK in 2012	NS	Access to this database was provided by the BAUS and was password privileged
57	Caskey F. Castledine C. Dawnay A. Farrington K. Fogarty D. Fraser S. Kumwenda M. MacPhee I. Sinha MD. Steenkamp R. Williams AJ	UK Renal Registry - Eighteenth Annual Report	2015	UK Renal Registry	Renal surgery	Renal Association, The Scottish Renal Registry, The British Association of Paediatric Nephrology, PatientView, The UK Registry for Rare Kidney Diseases (RaDaR), The Northern Ireland Nephrology Forum and The Welsh Renal Clinical Network.	The UKRR reports directly into the Renal Information Governance Board (RIGB) of the Renal Association. From the beginning, the management committee had representatives from the British Association of Paediatric Nephrologists (BAPN), the British Transplant Society (BTS), the Scottish Renal Registry (SRR) and patient organisations.	To facilitate improvements in patient care by auditing against national standards and supporting research, innovation and quality improvement.	The UK Renal Registry (UKRR) was established by the Renal Association in 1995 as a resource for the development of patient care in renal disease	Initially funded by the Department of Health and industry (1995), but within two years was financially independent of both. It is now principally funded through an annual capitation fee levied on renal replacement therapy (RRT) patients; this currently (2016) stands at £27.50 per patient in England and £22.50 in Wales and Northern Ireland , levied as separate fees for the UKRR and PatientView on dialysis and transplant patients and representing less than 0.08% of the average annual cost of treating these patients. Some projects and collaborations receive funding through linkages with other organisations or grants for research and development.	The idea of the dataset is to give a complete picture of every renal patient-demographics, comorbidity, test results, renal replacement therapy (RRT) and medication	The idea of the dataset is to give a complete picture of every renal patient-demographics, comorbidity, test results, renal replacement therapy (RRT) and medication	Data are collected on a quarterly basis via an automatic download from renal unit databases. Work with partners to ensure accurate extraction of data from NHS IT systems. They work with academics and others to ensure analysis is robust and accurate. Ensuring quality assurance and quality improvement is built into all aspects of the registry. The registry can capture real-time data from renal centres. The UKRR and the Health and Social Care Information Centre (HSCIC) have agreed that there could be considerable benefits for patients from routine linkage with Hospital Episode Statistics.	High quality clinical databases open to requests from researchers. Participation is mandated in England through the NHS National Service Specification and the Chief Executive of each Trust is responsible for adherence to this contract.	UKRR collects, analyses and reports on data from 71 adult and 13 paediatric renal centres	Annual reports in a form that are easily accessible to patients, clinicians, commissioners, policy makers and anyone with an interest in renal disease.	There is a Patient Council that: Act as representatives for kidney patients and their carers; Guide and influence methods of delivery of care; Advise on opportunities for new work ideas and initiatives for the UK Renal Registry (UKRR); Contribute to the development of new audit, research and survey proposals; Provide an arena that will encourage discussions between patients and clinical teams to promote patient involvement at renal centre, regional and national levels; Monitor and review patient facing initiatives recommended by the Department of Health; Review applications and contribute towards the production of patient leaflets, posters, reports and other patient information products developed by the Renal Association;	NS	Registries can improve the health of the population in many ways. Their data can be used to generate and refine hypotheses that require testing, to inform optimal study design, to provide the evidence of need for the research to help secure funding, to provide an efficient framework for sampling and data collection in trials, to track changes in practice and finally and most importantly to monitor changes in population health outcomes. The registry is able to support an efficient randomised controlled trial (SIMPLIFIED) by providing daily feeds of laboratory data for patients consented into the trial. All follow up for the trial is being carried out remotely with linkage to routine databases. The trial is called SIMPLIFIED and tests the hypothesis that ordinary vitamin D given to dialysis patients reduces all-cause	NS	The UK Renal Registry is part of the Renal Association, a not for profit organisation registered with the Charity Commission. They try to ensure that all data are extracted, stored and used in line with good information governance and Caldicott principles. Permissions for the UKRR to undertake research and linkage with data have had to be established and it has become clear that research ethics committee approval is needed for all work that is not audit or quality assurance. The registry approves a number of requests for data sharing. Data are shared for specific analyses only and securely destroyed at the end of the agreed period. The UKRR operates within a comprehensive governance framework which concerns data handling, reporting and research, including data linkages and sharing agreements. The UKRR has temporary

															Support the UK in issues relating to information governance and patient consent; Use personal networks to spread awareness of the UKRR and its work with the council; Occasionally represent the Patient Council and the UKRR at other external meetings.		mortality. In the last year the registry has been a co-applicant on four grant applications		exemption, granted by the Secretary of State for Health under section 251 of The National Health Service Act (2006), to hold patient identifiable data. This exemption is reviewed annually. The UKRR has successfully completed the Connecting for Health information governance toolkit to a satisfactory standard
Sabah S.A. Henckel J. Koutsouris S. Rajani R. Hothi H. Skinner J.A. Hart A.J.	Are all metal-on-metal hip revision operations contributing to the National Joint Registry implant survival curves?.	2016	National Joint Registry	Hip surgery	NS	NS	To examine the data quality of the NJR and to validate data quality on metal-on-metal hip revision procedures.	NS	NS	NS	NS	This study showed that only one third of retrieved components at the London Implant Retrieval Centre, contributed to survival curves on the NJR, this suggests that current NJR data on failure rates may be vulnerable to missing data. The most likely explanation for this appears to be the poor rate of consent, compliance and linkability during the early years of the NJR. The authors recommend that the NJR provide outcome data only for the periods where it has achieved excellent data collection. They also advocate for registry: retrieval linkage to become an integral component of the NJR Data Quality Strategy - this would enable feedback on errors and missing data and improve data quality.	NS	This study showed that only one third of retrieved components at the London Implant Retrieval Centre, contributed to survival curves on the NJR, this suggests that current NJR data on failure rates may be vulnerable to missing data. The most likely explanation for this appears to be the poor rate of consent, compliance and linkability during the early years of the NJR. They found that for the procedures the NJR did record, data quality was excellent. There was no missing data for surgical unit, date of revision, procedure type and implant side. This reflects the engagement from surgeons and Hospital Data Managers and the high quality of the NJR database infrastructure	NS	NS	NS	Large data sets are very helpful for planning provision of health care and to study disease patterns	NS	NS

59	Suradi H.S. Hijazi Z.M.	TAVR update: Contemporary data from the UK TAVI and US TVT registries.	2015	UK TAVI Registry	Transcatheter aortic valve replacement (TAVR)	NS	NS	This paper discusses two recent registry results, reflecting the TAVR experience in the United Kingdom (UK) and the United States (US). We are only collecting information specific to the UK registry	NS	NS	NS	NS	NS	NS	NS	NS	NS	NS	Registries represent the "real world" experience. Provides good analysis of trends and risk factors for mortality and results. The UK TAVI registry represents the largest long-term experience of an entire country to date with up to 6 years follow up. It lets you look at long term outcomes and track which type of patients are receiving the procedure. Even though there are 3 RCTs looking into TAVR, the registries are reflective of "real world" clinical experience and enable long term tracking of outcomes.	NS	NS
60	Chou E. Abboudi H. Shamim Khan M. Dasgupta P. Ahmed K.	Should surgical outcomes be published?.	2015	Review articles on publication of surgical outcomes	All surgery	NS	NS	This article aims to address whether surgeons should publish their outcomes, its pros and cons as well as the challenges faced.	NS	NS	NS	NS	NS	NS	NS	In terms of publishing surgical specific outcomes, one of the main factors holding this initiative back is the difficulty in taking into account the complexity of different cases across the numerous specialties, to produce clinically valid results. The benefits of publishing surgeon specific outcomes include: Increased transparency and patient trust, increase patient centred care, helps surgeons compare their performance, it has been shown to reduce mortality rates, consultants pay closer attention and provide closer supervision to their juniors, it helps measure clinical effectiveness. DIsadvantages include: misrepresented outcomes, patients may not understand limitations with outcomes, may result in loss of skilled surgeons, less training opportunities for trainees, surgeons may not take on complex cases. To help facilitate publication of surgeon specific outcomes, it is imporant to	NS	NS	National clinical audits are considered to be the gold standard in measuring outcomes	NS	NS

														statistically adjust for case-mix. Another factor is that surgical outcomes are not solely dependent on the consultant as other members of the operating team also contribute. It is thus important that team-level data are published as well to reflect the complex interplay of the multi-disciplinary team. The benefits of reporting patient outcomes seem to outweigh the disadvantages, and they should be published.							
Breakwell LM Cole AA Birch N Heywood C	Should we all go to the PROM? The first two years of the British Spine Registry.	2015	British Spine Register	Spinal surgery	The British Association of Spine Surgeons, the British Scoliosis Society (BSS) and the Society of British Neurological Surgeons	BSR Steering Committee	The purpose of the BSR is to collate information on the current state of spinal surgery within the United Kingdom in order to identify areas of best practice and so facilitate improved patient care	The British Association of Spine Surgeons instituted the design, construction and rollout of the British Spine Registry. The BSR, built on the Amplitude platform, (Amplitude Clinical, Droitwich, Worcestershire) was constructed to be a secure Internet based repository freely available to the societies' memberships.	Recent funding support from NHS England. Recurring funding to ensure expansion of the Registry is being sought independently of the spine societies.	Collection of outcome measures after surgery, including patient reported scores is central to the function of the BSR. To give a more reliable overview of current spinal activity in the United Kingdom a mandatory dataset has been determined. The BSR team decided to collect PROMs for specific procedures at predetermined time points.	The standard patient questionnaires will include the EuroQoL EQ-5D,26 a visual analogue score for back and leg pain and the Oswestry Disability Index. A satisfaction assessment akin to the Friends and Family tool will also be used at the final follow-up stage	The surgical team can enter scores retrospectively after paper form collection or the data can be entered prospectively by the patient themselves either via an email portal, a personal computer, a tablet or a smartphone while the patient is in outpatients. To this end, the BSR is in discussion with NHS England, the National Institute for Health and Care Excellence, HQIP, the Private Healthcare Information Network and the Association of British Healthcare Industries, amongst others, to enshrine the BSR as the central resource for spinal surgical data for the United Kingdom.	Until mandatory status is achieved, it is unlikely the true value of the BSR will be realised. At present, this is largely beyond the direct control of the Spine Societies, but progress made through the British Orthopaedic Association's Quality Outcomes Committee. Since 2009 it has been a mandatory requirement for all facilities providing care to NHS patients undergoing hip and knee arthroplasty, groin hernia repair and varicose vein surgery to participate in the national PROMs programmes. The BSR has been designed to enable multiple modes of capture, either by secure email, or via touchscreen input on a tablet or kiosk computer while the patient is in outpatients, which should reduce questionnaire fatigue. Support is needed from NHS trusts and private providers that offer NHS treatment in terms of recognition of the time and logistical requirements of capturing this type of data on large numbers of patients. Need the support and input of the appropriate stakeholders. Raising awareness of the	Since its launch in 2012, over 650 users have registered more than 27 000 patients onto the database. These users include representatives from all aspects of the surgical team including surgeons and nurses, to admin assistants, physiotherapists, secretaries and doctors in training. At the 2014 annual scientific meeting of the BSS in Bristol, it was announced that the Society aimed to achieve 100% data capture by the end of 2016. Current uptake of the registry is 15%	NS	Data can be entered prospectively by the patient themselves either via an email portal, a personal computer, a tablet or a smartphone while the patient is in outpatients. Over 12,000 forms have been directly submitted by patients themselves.	There are difficulties around the recording of outcomes following spinal interventions, often because of the heterogeneous nature of the conditions being treated, as well as the significant psychosocial component of patients' presentations. It is uncertain whether the validated and widely accepted generic and disease-specific tools that are currently in use truly discriminate between good and bad operations. In some circumstances they have been shown to be inadequate. Limited outcomes tools may not be able to express fully the true extent of the patient's experience, but they are a start. Practical problems remain with regard to the collection of data, including patient engagement. Many units struggle to facilitate data entry due to the pressures of numbers in clinics and poor infrastructure investment at hospital level. The funding to enable collection is limited, despite the national mandate to do so.	Allow comparison of unit level results such as deep infection rates in scoliosis correction surgery. NHS trusts in England are already obliged to provide PROMS outcomes for surgery, but this has been implemented in a patchy and haphazard manner - the BSR is a valuable resource that would allow a systematic implementation of this policy. SR already gives a national picture of spinal surgery including case mix, volumes and trends, which informs debate and policy making. An additional intention of the design is to facilitate national research via multicentre trials supported by a low-cost data capture system that is secure, reliable and accessible.	Registry can be defined as 'a systematic collection of a clearly defined set of health and demographic data for patients with specific health characteristics, held in a central database for a predefined purpose'. Registries have limited value unless the data entry is relevant and complete.	Secure Internet based repository. Currently, surgeons and their teams, under the auspices of the Societies, own and control the data on the BSR - this should ensure the accuracy and reliability of such information with specific reference to the surgical detail

													registry is vital through wider publicity. Currently, surgeons and their teams, under the auspices of the Societies, own and control the data on the BSR - this should ensure the accuracy and reliability of such information with specific reference to the surgical detail							
AuditData	AuditBase	2016	AuditBase	Otology	Six expert implant teams in England, Scotland and Wales have given input to develop the database	NS	To increase efficiency	User-friendly and easy to navigate. Integrates all audiology disciplines in one system for maximum flexibility and resource management. Six expert implant teams in England, Scotland and Wales have given input to develop the database	Self funded	NS	Patient demographics, GP information, medical background, Pre-op assessment, contact details, baseline hearing (audiograms and other hearing tests), date of surgery, Ear side, surgical approach, implant details, surgical consent including date, Pre and post operative information, surgical information, 2 to 5 months after surgery , over one year after surgery, recording patient drop out; air conduction, bone conduction, air-bone-gap, graphical overlay of audiograms, sisual indicator of Belfast rule of thumb success, Histograms of trends in air and bone means over extended periods, OAE, ABR and CERA measurements, 32 speech and language and speech discrimination tests summary score screens, name of clinician, CT/MRI scans, patient questionnaires regarding their results	Advanced connectivity between AuditBase and Hospital systems.	Data is easy to access, user-friendly and easy to navigate. Integrates all audiology disciplines in one system for maximum flexibility and resource management. Core data entry forms. A checklist to ensure that all the neccessary steps have been completed, easy access to data for research purposes, can use the registry from remote (off-site) locations, allows complete exporting of data to Excel, has built in patient reports with hearing results. Helps you send letters to patients and healthcare professionals. Can also be used to send mobile phone text reminders to patients for clinics and operations.	Used in more than 80% of all hospital audiology clinics in the UK and Scandinavia. More than 4500 users in over 500 audiology clinics.	The system helps you generate audit reports	NS	NS	Enables you to plan and easily visualise a patients pathway. It can help you keep control of expenditure and gain funds from commissioners. Gives you information on patient preferences. Helps you report data. Helps you manage stock levels and help with managing purchase ordering.	NS	AuditBase is CE-marked as a medical device (class I) under the EU Medical Device Directive. It is registered with the UK ICO-Information Commissioners Office (required by the Data Protection Act). N3 and ISO 27001 (information security) certified. Completed the NHS Information Governance Statement of Complicance and therefore comply with all legal requirements of the NHS to safeguard patient confidentiality.

Yung M, Gjuric M, Haeusler R, Van de Heyning PH, Martin C, Swan IR, Tange RA, Huy PT, European Otology Database Project Group	An international otology database.	2005	International otology database.	Otology	A working party of 27 otologists from 12 countries in Europe has already agreed on the content of a common ear database. The project group members include otologists from the United Kingdom, Belgium, Switzerland, France, Germany, Croatia, Hol- land, Sweden, Poland, Slovak Republic, Denmark, and Hungary.	NS	This paper proposes an International Otology Database. The aims of the project are: To identify common otology audit data among clinicians; To provide an information technology system to store otology data for clinicians; To create a large database that allows statistical analysis to be made on various otologic interventions with sufficient power; To produce standards or benchmarks for compar- ative audit. The web-based system can be a useful learning tool for surgeons because it gives almost real-time feedback to the individual surgeon. This enables clinicians to monitor their own surgical practice against these standards. The Surgical Training Committee can even use it as a tool to implement competency-based training for surgical trainees; The system provides the mechanism for hospitals or clinicians to collaborate in clinical trials using the common data input methodology; The ultimate goal of the proposed project is to provide primary potential research data that is lacking at the moment.	Web-based, prospective data entry. The data entry is either by tick boxes or selections from drop-down boxes. Input errors are validated using information technology techniques to make sure that all data fields are completed. There should be international consensus on the content of the proposed database. A working party of 27 otologists from 12 countries in Europe has already agreed on the content of a common ear database. The project group mem- bers include otologists from the United Kingdom, Belgium, Switzerland, France, Germany, Croatia, Hol- land, Sweden, Poland, Slovak Republic, Denmark, and Hungary.	NS	There should be international consensus on the content of the proposed database. The system must be user-friendly, in both data input and retrieval.	Patient details, proposed operation date, pre-operative symtpoms, aim of surgery, risk factors, audiogram results, operative findings, operative details (approach, materials used), complications, pathology results, audiogram, follow up intervals, main outcomes, free text for comments. Two levels of data entry are available: Level 1 (a minimum otology database): This is designed for general otolaryngologists and surgical trainees. Only main surgical outcomes are recorded. Level 2 (a comprehensive database): This is designed for dedicated otologists. Detailed information on pathologies, risk factors, and surgical procedure are recorded.	Input errors are validated using information technology techniques to make sure that all data fields are completed. Bias reporting or incorrect data entry will contaminate the quality of the ''benchmarking database.'' Therefore, validation of input data is important. This can be done by site visit of each hospital by an external inspector/auditor (another user of the web-based system) to perform random inspection of patient records. Data used as a benchmark or 'standards' are validated	Users of the database should not be exclusive to a few selected otologists. The otology audit system is available to any surgeons who perform middle ear operation in Europe. Every data field on the data entry form needs to be completed before the form is accepted by the website, thus ensuring completeness of data entry. The data entry is either by tick boxes or selections from drop-down boxes. Pilot the registry. The registry needs to be easy to use and flexible,	NS	The identity of surgeon and patient must remain anonymous. Outcome data used for benchmarking is validated	NS	NS	Help drive evidence based medicine, helps produce standards or benchmarks for comparative audit between surgeons and centres, provide real time feedback to the individual surgeon, help develop standards for surgical training, helps provide evidence of quality assurance, helps with commissioning, helps with surgical self audit. Allows statistical analysis to be made on various otologic interventions with sufficient power owing to large amounts of data, helps facilitate clinical trials and research.	NS	Each surgeon is allocated an access code and a password. They can change their own password once they log in. The identities of the patients and the surgeons are anonymous. Each hospital would be given a Hospital Code Number and each surgeon a Surgeon Code Number. Each patient is identified on the database with an encrypted Patient Code Number created by the individual surgeon

64	Yung M, Heyning P	A Prospective Multicentre Otology Database	2007	Prospective Multicentre Otology Database	Otology	There should be international consensus on the content of the proposed database	NS	Aim of the project is to create an interactive otology database for surgeons in the UK and Europe. The aims of the project are: To identify common otology audit data among clinicians; To provide an information technology system to store otology data for clinicians; To create a large database that allows statistical analysis to be made on various otologic interventions with sufficient power; To produce standards or benchmarks for compar- ative audit. The web-based system can be a useful learning tool for surgeons because it gives almost real-time feedback to the individual surgeon. This enables clinicians to monitor their own surgical practice against these standards. The Surgical Training Committee can even use it as a tool to implement competency-based training for surgical trainees; The system provides the mechanism for hospitals or clinicians to collaborate in clinical trials using the common data input methodology; The ultimate goal of the proposed project is to provide primary potential research data that is lacking at the moment.	There should be international consensus on the content of the proposed database. The system must be user-friendly, both in data input and retrieval. A working party of international otologists from 11 countries has already agreed on thecontent of a common ear database. Web-based and prospective. Piloting the registry is useful for user feedback.	NS	NS	Patient details, proposed operation date, pre-operative symtpoms, aim of surgery, risk factors, audiogram results, operative findings, operative details (approach, materials used), complications, pathology results, audiogram, follow up intervals, main outcomes, free text for comments. Two levels of data entry are available: Level 1 (a minimum otology database): This is designed for general otolaryngologists and surgical trainees. Only main surgical outcomes are recorded. Level 2 (a comprehensive database): This is designed for dedicated otologists. Detailed information on pathologies, risk factors, and surgical procedure are recorded.	Data used as a benchmark or 'standards' are validated. The methodology requires surgeons to put in pre-operative data on all patients scheduled for ear surgery, thus eliminating bias from selective reporting of operations. Validation of data can be done by site visit of each hospital by an external inspector/auditor (another user of the web-based system) to perform random inspection of patient records. The benefit of using peers to validate data from each centre gives a further opportunity for clinicians to learn from each other.	The system must be user-friendly, both in data input and retrieval. The use of the database should not be exclusive to a few selected otologists. Every field on the data form needs to be completed before the form is accepted, thus ensuring completeness of data entry. Each surgeon can download his surgical results from the website into an Excel file in almost real time	NS	The identity of surgeon and patient must remain anonymous; data used as a benchmark or 'standards' are validated	NS	NS	To help facilitate comparisons and establish standards. To facilitate research.	Help generate data quickly for clinical trials.	The identity of surgeon and patient must remain anonymous. Each surgeon is allocated an access code and a password. Data will owned by all the members who contributed
65	Health and Social Care Information Centre	National Head and Neck Cancer Audit, Tenth annual report	2014	National Head and Neck Cancer Audit	Head and Neck Cancer surgery	The Healthcare Quality Improvement Partnership (HQIP), Health and Social Care Information Centre (HSCIC), The British Association of Head and Neck Oncologists (BAHNO)	The professional body overseeing the Audit was the British Association of Head and Neck Oncologists (BAHNO)	The aim of the Audit is to improve quality of care to those patients with head and neck cancer by raising standards of care to match those of the best performing teams.	NS	The Audit was commissioned by the Healthcare Quality Improvement partnership (HQIP) and funded by NHS England and the Welsh Government.	Measures for cancer outcomes have been drawn from the National Institute for Health and Care Excellence (NICE) published guidance on head and neck cancer - this facilitates comparison of practice to national guidance. The Patient Concerns Inventory (PCI) is a tool that helps patients more effectively voice concerns during their follow up, with the aim of better holistic care. For the first time the Audit has collected information on the use of this tool and in future better understanding of	Patient demographics, Patient Concerns Inventory, mortality, treatment received, four year survival, speech and language assessment, time to treatment. Human Papilloma Virus (HPV) status. Whether HPV was tested. Whether there was an MDT discussion. Length of stay. Complications.	Analysis was performed by the HSCIC analysis team, and interpretation of data was facilitated by an Expert Panel of head and neck professionals. It is useful to supplement and link audit data with external data sets such as HES to increase accuracy. Casemix adjusted mortality ratios provide a more meaningful way to compare outcomes between cancer networks. This allows networks to be scored as to whether the mortality rate falls outside expected levels. Combination of	Publicising the registry. Having a restricted data set has led to higher levels of data completeness - it is important to have for focused and targeted questioning. It is important to provide staff with adequate support and resources to submit data.	The Head and Neck Cancer Audit database contains information on more than 54,000 head and neck cancer cases, with 7,700 cases of cancer of the glottic larynx, and more than 7,500 cases of oral tongue cancer. Only a small percentage of patients completed the PCI. Trust participation in the tenth Annual Report is estimated at 96 per cent. 86.0 per cent of patients had treatment recorded; 86.3 per cent in	The report was produced by the National Head and Neck Cancer Audit Project Team under the auspices of the HSCIC.	Patients concerns inventory (PCI) This is a tool that helps patients more effectively voice concerns during their follow up, with the aim of better holistic care. This is the first time the Audit has collected information on the use of this tool. In this data period only a small percentage of patients completed the PCI, but by publicising it more widely we would hope to see greater uptake in future.	Difficult to get data completion on patient concerns inventory. Difficult to supplement/link the audit data with other data sets like HES which would help make the data more robust.	Helps identify national variation in services. Enables you to check whether guidelines are being met. Enables comparisons of practice between centres, helps inform patients about their disease and potential outcomes. The registry data can also be used to answer questions where existing evidence is lacking. Registry data can also help you map and evaluate the patient pathway. Helps commissioners and providers	NS	NS

									the actual responses may help direct appropriate support for patients and their carers.		different data sources is both feasible and has led to significant added value		England and 82.1 per cent in Wales.				of care reflect on their performance and develop actions to improve. Helps improve standards of care. Faciliates research. Enables monitoring of NHS standards of care and supports service reorganisation and appropriate commissioning.		
66	Hopkins J Welbourn R	The importance of national registries/databases in metabolic surgery: the UK experience.	2016	National Bariatric Surgery Registry	Bariatric surgery	British Obesity and Metabolic Surgery Society, the Association of Laparoscopic Surgeons of Great Britain & Ireland, and the Association of Upper Gastro-intestinal Surgeons, Dendrite Clinical Systems Limited	NS	The aim of this paper was to present the baseline patient characteristics, type 2 diabetes outcomes, and main operation results from January 2009 to December 2013, incorporating the data from the first 2 book reports, and compare them with other national registries.	The NBSR is a web-based application developed to collect prospective data for all bariatric surgery patients in the UK and Ireland.	Seed funding provided by the Association of Laparoscopic Surgeons of Great Britain & Ireland	NS	Patient demographics, co-morbidities, primary or revision surgery, type of surgery, funding of surgery, BMI, diabetic status, post of complications, date of discharge, destination of discharge, mortality, cause of death, weight loss.	Data are typically collected and submitted during routine clinical visits pre and postoperatively. To provide external validation, the NBSR also analysed NHS administrative data that is independently collected. As a cross check, data were compared to the ONS	Minimise the dataset, be selective with data collection fields. In April 2012, the NBSR became mandatory for NHS provider units. Data completeness in the NBSR has improved to over 90% since it became mandatory. Promote a culture of submitting data routinely.	Produced outcomes reports in more than 25,328 patients. Data completion of over 90%.	The registry had individual consultant surgeon mortality data published for the years 2012–2014	NS	One of the biggest challenge of any registry is collecting long term outcomes. Another key challenge is agreeing on core outcome sets and trying to make this compatable with international registries.	Registries provide commissioners and decision makers with robust and real world data that help them make decisions. Registries can influence policy: the NBSR has influenced NICE guidance. Helps drive quality improvement. Registries improve the profile and acceptance of metabolic surgery amongst payors and commissioners. Registries can indicate which patients have the greatest likelihood of success from the operation, which is important in the NHS, where rates of surgery are rationed to a fraction of those deemed eligible by national guidelines. Can help identify variations in practice within the UK but also between different healthcare systems.	NS	Access is via a unique password-protected ID for registered surgeons and their named delegates. Each user sees only their own data and access to the database as a whole is restricted to system administrators, with data release controlled by a database committee. Patient data are anonymised to comply with the UK Data Protection Act 1998, with a unique ID number allocated to each patient at the point of initial data entry. In the published NBSR reports, only aggregated data are reported without identifying any patient, surgeon, or unit.
67	National Institute for Health and Care Excellence	Interventional procedures programme manual. Section 12.3	2016	NS	NS	NS	Independent steering group should be responsible for design, data monitoring and analysis.	This section provides NICE standards and criteria for recommending a register in Interventional Procedures guidance	The register should be recorded on national database of registers. Medicines and Healthcare products Regulatory Agency/NICE and professional representatives should be involved in dataset design and agree the final design.	NS	In their guidance documents, NICE specifies the outcomes that are most needed. This can be looked at when developing a national registry.	All known procedures (all devices), without exception, are recorded in the database. Efficacy and safety outcomes and important patient characteristics.	Process for data collection, storage and analysis independent of any particular company or any commercial interest.	NS	NS	There should be explicit intent to publish results whatever the outcome.	NS	NS	When data on efficacy or safety are inadequate in quality or quantity, registry data can enable NICE to review and update their guidance. Registries are useful for providing efficacy and safety data. Registries also encourage audit of outcomes.	NS	Data should be anonymised. The Registry must comply with the data protection principles laid out in the UK Data Protection Act 1998 and any other relevant legislation. The data should be used fairly, for specific purposes, the data should not be kept for longer than is necessary, the data should be kept safe and secure, and not transferred outside the European Economic Area without

																				adequate protection
68	PELICAN	LOREC APE Perineal Wound Registry	2016	NS	Abdominoperineal excision	NS	Steering committee. The registry is maintained by LOREC	The objective is to find out which aspects of each procedure (for abdomino perineal excision) are most successful for patients in terms of complication free wound closure and healing.	Online registry hosted on LOREC website.	NS	NS	NS	NS	NS	NS	NS	NS	NS	Provides data on current practice and outcomes.	NS	There is a data custodian. The registry leads have access to all the data.
69	Uberoi R. Milburn S. Moss Jon. Gaines P.	British Society of Interventional Radiology Iliac Artery Angioplasty-Stent Registry III	2009	BSIR Iliac Artery Angioplasty-Stent (BIAS) registry	Iliac artery intervention	NS	NS	Setting standards of practice for interventional radiologists carrying out iliac interventional procedures	Based on a previous BIAS registry. Access to the registries could be obtained either through the BSIR Web site or directly at the Dendrite Web site.	The registry is funded by the BSIR on behalf of its members.	Based on a previous BIAS, the data sets were modified so that the number of data collected from each procedure was reduced and free text was minimised.	Type of intervention, patient demographics, co-morbidities, day-case or inpatient, level of clinician, indication, elective/emergency, procedure details, outcome, complications.	Data were collected and analyzed by Dendrite Clinical Systems	Minimise the dataset and amount of free text. Online collection of data. Increase pressure for clinicians to self-audit. External motivation in the form of regular feedback, newsletters, and follow up e-mails requires funding and staff.	Over a 43-month period (2005 to 2008) 37 institutions submitted data for 2233 patients. This brings the total BIAS database to 4295.	NS	NS	It is challenging to achieve good rates of data completion. This is likely due to lack of time and motivation. It is also difficult to capture long term follow up data. Limited resources.	Provide a structured format for collecting data. Allow comparison of an individual's performance with that of others, highlighting areas which are done well and those in need of improvement. Enables assessment of trends in practice. Enables individuals to carry out regular audits and comply with local and national requirements for appraisal and revalidation.	NS	NS
70	Goode SD. Cleveland TJ. Gaines PA	United Kingdom Carotid Artery Stent Registry: Short- and Long-Term Outcomes	2013	UK CAS Registry	Carotid artery stenting	NS	NS	To monitor the practice of CAS with the aims of gathering short and long-term data to better inform our practice.	Set up by BSIR. Voluntary registry open to all UK hospitals.	NS	NS	Demographics, comorbidities, indications, location of disease, procedure inforation, 30-day outcomes, complications.	Data were self-reported and collated by a clinician entering data into the registry. A follow-up form was sent to each centre on an annual basis. Centres that had not returned follow-up forms were sent another form and followed-up by a telephone call. All data were entered onto a clinical database provided by Dendrite Clinical Systems.	Data entry into the registry was encouraged by the publication of the National Institute of Clinical Excellence (NICE) guidance, which advised that data of all patients undergoing CAS should be entered into UK CAS registry held by the BSIR	NS	NS	NS	NS	Enables monitoring of practices.	NS	NS