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Can health technologies be assessed using routine data?

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Objectives: The potential of routine data for health technology assessment (HTA) in the United Kingdom was assessed.
Methods: Compiled were a comprehensive list of routine databases, their classification according to data characteristics, literature review on their current use, and their comparison with key topics identified as priorities for HTA.
Results: Two hundred seventy health-care databases for England or the English regions were identified. Twenty-four included data on both health technology and patient health state. Eleven found some published use in effectiveness evaluation. Of 140 prioritized health technologies, only 22 could be identified in routine databases.
Conclusions: Routine data are plentiful but of limited use in HTA. The data sets usually do not include the effect of treatments. Coding is inadequate, and confidentiality regulations will make matters worse. Both need urgent attention.

Keywords: Routine data, Administrative data, Health technology assessment, Health-care evaluation, Disease registers, Registries

Three decades of continuous growth of evidence-based medicine and health technology assessment (HTA), from Cochrane's critique of effectiveness and deficiency (6) to the birth and entrenchment of the National Institute of Clinical Excellence have amounted to a revolution in the knowledge-base health care, not just in Britain but internationally. This revolution is voracious in its appetite for information on the effectiveness of health technology. Conventional scientific wisdom favors ever more and larger randomized controlled trials (RCTs) collecting customized data. Concealed randomized allocation of interventions prevents selection bias and controls for confounders, both known and unknown. However, there are limitations to trials. First, the scale and pace of health technology developments is greater than the capacity to fund and carry out RCTs. Second, RCTs may occasionally be inappropriate, impossible, or inadequate for health technology assessment (4).

Observational studies, which wholly or in part use routine data, could provide a potential alternative or complement to randomized controlled trials. Particular RCT limitations relevant to routine data are that RCTs may not be generalizable to routine everyday practice and they are often not large enough or long enough to detect adverse events. However, routine data have been little used in HTA. A vicious circle applies: as the data are poor, they cannot be used; lack of use ensures they remain limited and of poor quality.

In this study, we explore the potential of routine data in health technology assessment care through identifying all United Kingdom and English routine data sets: (i) assessing how many of these data sets have prima facie characteristics necessary for HTA, (ii) reviewing the use that has been made of routine data in this way to date, and (iii) investigating what use could be made of routine data for a national set of prioritized health technologies for assessment (15).

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METHODS

We define routine data to be data that have regular and continuing collection, use standard definitions, include some degree of obligation to collect the data completely and regularly, and are collected at the national or regional level. We, therefore, interpret the term routine data widely to include not only administrative data sets but also disease and health technology registers, adverse event reporting systems, and regular health-related surveys.

Identification of Routine Health and Health-Care Databases

No comprehensive list of routine databases was available in the United Kingdom. We compiled the list through a combination of the use of key literature sources, references from within those sources, and a network of people with experience of routine databases. The key literature sources in this field turn out to comprise mostly books, book chapters, and health service circulars and official publications rather than journal articles (1;5;9;14;16;18;22;32). Private-sector databases were explored using the published literature and a survey of the major UK health insurers.

Classifying Database Characteristics

To be of value in HTA, databases must at least identify both the health-care intervention or setting ("a health technology") and user characteristics of patients receiving the technology, particularly their health state. We classify such databases as group 1 databases. We also classify as group 2 databases those that identify a health technology but not a health state, and group 3 as those databases identifying health states but not a health technology. The relevance of group 2 and 3 is limited in health-care evaluation but can be used for assessing diffusion and equity in the case of group 2 and, occasionally, for identifying adverse events in the case of group 3. These databases are not considered further here.

Current Use of Routine Data in Health-Care Evaluation

The use of databases in HTA was identified by literature searches, which both include synonyms of routine data plus use, and separately the title of each database as a key word. In addition, annual reports of databases were examined and database "keepers" were queried. Each identified use was checked by the three principal investigators.

Potential Use of HTA

The UK National Health Service (NHS) Research and Development (R&D) Health Technology Assessment program has been charged since 1992 with prioritizing key elements of health care of importance to the NHS, which require evaluation (8). Details of 142 topics funded up to February 2000 by the NHS R&D Health Technology Assessment program were reviewed by the principal investigators (15). Each project was scrutinized for the extent to which it could, in principle, be picked up by group 1 databases.

RESULTS

Identification of Routine Data Sets

Two hundred seventy databases were identified that covered the United Kingdom, its constituent countries, or one or more of the English regions. To avoid duplicate analyses, we excluded over 700, which were duplicates for Scotland, Wales, or Northern Ireland. Data sets unique to any of these countries, meeting the definition, were included. Table 1 lists the 24 data sets (9%) classified as group 1, that is, they included

Table 1. Routine Databases Incorporating Both Health Technology and Patient Data, UK/England, with Summary Indication of Use in Any Kind of Health-Care Evaluation up to December 2000

	Ever used (refs)
Clinical administrative databases	
Hospital Episode Statistics	Yes (17)
General Practice Research Database (GPRD) (+ similar databases)	Yes (2)
National/Regional Cancer Registries (incl. Leukaemia registers)	No
Clinical Registries	
British Cardiovascular Intervention database	No
Human Fertilization and Embryology Authority (HFEA) data set	Yes (27)
Intensive Care Audit and Research Centre (ICNARC)	No
National Breast Implant Register	No
National Pacemaker Database	No
National Prospective Monitoring system (HIV/AIDS)	Yes (3)
National Transplant Database	Yes (7;19;31)
Northern Region Leukaemia database	No
Scottish and Newcastle Lymphoma database	Yes (13;26)
St. Mary's Maternity Information system	No
Trent hip register	No
UK Cardiac Surgical Register	No
UK Cystic Fibrosis Register	No
UK Haemophilia centers Directors Database	No
UK Heart Valve Register	No
UK Hydrocephalous Shunt database	No
UK Renal Register	Yes (24)
UK Thalassaemia Register	Yes (23)
Population Databases	
Immunization programs	Yes (take up) (12)
Cervical Cytology Screening Programme	Yes (take up) (11)
Breast Screening Programme	Yes (take up) (10)

AIDS, acquired immunodeficiency syndrome; HIV, human immunodeficiency virus.

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some information on both health state and intervention. This group included three clinical–administrative databases: the Hospital Episode Statistics (HES), the General Practice Research Database (GPRD), and the National and Regional Cancer registries. It included eighteen clinical registries (such as the British Cardiovascular Intervention Society database and the Human Fertilization and Embryology Authority [HFEA] database). It also included three aggregated databases of interventions applied to whole populations that, although not identifying individual patients, could conceivably be used to assess the effectiveness of specific population-oriented interventions, such as screening and immunization program.

Current Use of Group 1 Databases

Of the twenty-four group databases, eleven had found some published use in effectiveness evaluation (Table 1). This group included two of the clinical administrative databases, that is, the HES and the GPRD, but not the National and Regional Cancer registries. However, for the HES and GPRD, only one reference that came close to HTA or health-care evaluation was found, for each (2;17). Among the qualifying disease registries, six had shown some use, notably the HFEA database, which has been used to show factors associated with a successful fertility treatment birth (27), and the National Transplant Database, which has been used to show the benefits of HLA matching (19;31) and to identify the best methods of cadaveric organ retrieval (7). The Scottish and Newcastle Lymphoma database has been used to evaluate treatment and outcome for all newly diagnosed patients with Hodgkin's disease (26) and to explore the long-term effects of autologous bone marrow and peripheral blood stem cell on the loss of fertility (13). The national prospective human immunodeficiency virus (HIV) monitoring survey has been used to assess intermediate outcomes such as viral load in HIV patients (3). The UK Thalassaemia register has been used to assess the outcomes of screening for affected couples (23). Of the aggregated population databases, use has been made of the immunization program's database, the cervical cytology screening program database, and the breast screening program database to measure uptake rates and, therefore, at least a proxy for the effectiveness of the program (10–12).

Potential Use

Table 2 shows the limited potential of current routine databases for capturing health technologies that were prioritized by the NHS R&D Health Technology Assessment program. Of over 140 technologies, only 22 could be identified in the routine databases. The bulk (sixteen) of these technologies were drugs prescribed in primary care, which are captured by the GPRD. The capture of these drugs by the Prescription Pricing Authority is of limited value for HTA, as this capture does not link the prescription to any disorder. No routine databases exist on hospital prescriptions. A few surgical procedures were identified but are limited by the imprecision of coding in the surgical procedure coding system, OPCS 4. In the registries, only dialysis in the UK Renal Registry and ultrasound in the St. Mary's Maternity Information system could be identified as specific interventions. However, even when technologies could be identified in any routine database, data were generally lacking on the relevant patient characteristics necessary to assess effectiveness.

DISCUSSION

There is clearly no shortage of routine data collected in the UK's NHS. But it is not so clear that there is a shortage of good routine data, that is, data that can be used for such exacting purposes as HTA. Although we were able to identify over 270 health-care databases covering the United Kingdom as a whole, one of the constituent countries, or an English region, only thirty-three of these databases both record a health technology and a patient health state—the basic minimum for evaluating the effectiveness of health care. These thirty-three, of course, include some important databases such as the HES and the cancer registries, but worryingly, when put to our two tests, that is, whether they are ever used and whether they are ever usable, there were very few positive findings.

Does the very low use of routine data for such purposes just reflect an ignorance or an unjustified skepticism of routine data or does it reflect their real flaws? In fact, routine data are widely used in clinical audit, that is, measuring the performance of individual units. But this use is not always consistent and well-defined and may not always demand impeccable data. More often that not, the data are supplemented by additional information such as case note review. In the case of HTA, the data requirements are very tight. Indeed, the requirements of randomized control trials for very high quality data throws into sharp contrast the quality of routine data.

The flaws in routine data are five-fold. First, health-care systems have historically lived in an "information-free" culture. The scale and diversity of health-care systems have hitherto limited data collection to highly aggregated returns. Most health-care systems have some data on the number of people admitted to hospital or drugs prescribed, often (particularly in the United States) for reasons to do with payment, but few have data on the effects of treatment.

Second, there are clearly data collection problems. Whereas details of patients' conditions and treatments are noted, they generally do not become available as data for analysis. They are usually held in bulky case notes, usually still hand-written, specific to the place of treatment, difficult to interpret, and sometimes hard to locate.

Third, there is the problem of inadequate coding. The International Classification of Diseases (ICD) and the OPCS 4 Classification of interventions are in general use. It is acknowledged that they are limited not only by the quality

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Table 2. HTA Topic Titles and Extent to which the Health Technology(ies) Are Identified

HTA topic titles	HTA identifiable in a routine database
Surgery in low back and radicular pain	Partly (HES as OPCS 4 codes H51.1 Lumbar radiopathy but not the specific type of operation.)
Microdiscectomy for lumbar disc herniation	No
Total hip replacement prostheses	No (In HES, OPCS4 distinguishes total hip replacement by primary/revision and with/out cement. Nothing on the type of prosthesis.)
Medical and surgical treatments of menorrhagia	No
Paramedic skills in prehospital trauma care	No
Infusion protocols in adult prehospital care	No
Paramedic prehospital management	No
Outpatient services for chronic pain control	No
Dialysis for end-stage renal disease	Yes (UK Renal Registry)
Treatment of benign prostatic hyperplasia (BPH)	No
Transurethral resection (TURP), laser vaporization (LVAP), transurethral needle ablation (TUNA), and microwave thermoablation (MTA) of the prostate	No
Alternative electrosurgical modalities to treat bladder outflow obstruction in men with BPH	No
Bone marrow transplantation and peripheral blood stem cell treatment for malignancy	Partial (In HES, OPCS 4: W30 is allogeneic BMT)
Laparoscopic, vaginal and abdominal hysterectomy	Partial (HES OPCS 4 Q07. Q08 = hysterectomy vaginal, abdominal. No laparoscopic coded).
Organization of vascular services	Limited (volume but not organization or quality in HES (OPCS4)).
Arthroplasty or reduction for subcapital fractures	Partial (HES: OPCS4 S42/S72. Arthroplasty WS5 S6.)
Different service models for the management of minor injuries	No
Midwife/nurse roles in the routine examination of the newborn	No
Nurse versus doctor-led outpatient care in a bronchiectasis clinic	No
Nurse practitioners and preregistration house officers in preoperative work-up	No
Endovascular aortic aneurysm repair	No
D&I ear patient or laboratory testing	No
Near patient testing in diabetic clinics	No
Near patient testing in primary care	No
Radiography of patients presenting with low back pain	No
Systematic review of detection, management and screening for prostatic carcinoma	No
Different strategies for detecting and managing prostatic carcinoma	No (No specific diagnostic or treatment data in Cancer Registers)
MRI for investigation of the knee joint	No
MRI in the DGH setting	No
Routine preoperative testing	No
Digital imaging in diabetic retinopathy	No
Spiral and ultrafast CT	No
Biochemical markers for myocardial injury	No
Endoscopy with *Helicobacter pylori* testing versus noninvasive *H. pylori* testing alone in the management of dyspepsia	No
Molecular prenatal diagnosis for Down's syndrome	No
Endoscopic ultrasound and gastrointestinal Cancer	No
Central line insertion project (DLIP)	No
Diagnosis of endometrial abnormality	No
Heidelberg Retinal Tomograph and the Laser Diagnostics Glaucoma Scanning System in detecting and monitoring glaucoma	No
Virtual Outreach	No
Asynchronous and synchronous telemedicine in dermatology – RCT-ASTID	No
Investigating patients with suspected pulmonary thromboembolism	No
Imaging for acute stroke	No
Molecular techniques in prediction and diagnosis of CMV disease in immunocompromised individuals	No
Monitoring blood glucose in diabetes mellitus	No

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Table 2. Conitnued

HTA topic titles	HTA identifiable in a routine database
Urine albumin testing for early detection of diabetic complications	No
Intravascular ultrasound imaging in coronary artery disease	No
PET in the NHS	No
Urgent assessment of chest pain in general practice	No
Magnetic resonance angiography: carotid artery stenosis and peripheral vascular disease	No
Tumor markers in pediatric oncology	No
Algorithm-guided diagnosis of acute abdominal pain	No
Prevention of venous thromboembolism in surgical patients	No
Early introduction of inhaled steroids in asthma	Partial (inhaled steroid use is linked to disease group in GPRD
Clinical medication review by a pharmacist of patients on repeat prescriptions in general practice	No
Wound care	No
Home parenteral nutrition	No
Antimicrobial prophylaxis in surgery	No
Alternative analgesics following day case surgery	No
Antimicrobial prophylaxis in total hip replacement	No
Symptomatic versus aggressive therapy in established rheumatoid arthritis	No
Antimicrobial treatments for acne	No
Beta interferon for multiple sclerosis	No (requires hospital prescription data)
Hypertonic saline, daily and alternate day rhDNase in cystic fibrosis	Partial (no data on hospital prescriptions. GPs prescriptions in GPRD)
Treatment of established osteoporosis	No
Longer-term clinical outcomes and cost-effectiveness of standard and new antiepileptic drugs	Partial (GPs prescriptions in GPRD)
Anti-viral therapy for mild chronic hepatitis C	Partial (GPs prescriptions in GPRD)
Intrathecal pump systems for giving opioids in chronic pain	No
Depot neuroleptic drugs	Partial (GPs prescriptions in GPRD)
Implantable contraceptives	Partial (GPs prescriptions in GPRD)
Statins	Partial (GPs prescriptions in GPRD)
Anesthetic agents in day surgery	Partial (GPs prescriptions in GPRD)
Treatments for severe psoriasis	Partial (GPs prescriptions in GPRD)
Treatments for atopic eczema	Partial (GPs prescriptions in GPRD)
Antipsychotics in severe schizophrenia	Partial (GPs prescriptions in GPRD)
Managing the dyspeptic patient	No
Tricyclic antidepressants, selective serotonin reuptake inhibitors, and lofepramine	Yes (GPs prescription in GPRD)
Routine influenza immunization in subjects 65–74 years of age	No
Inhaler devices in asthma and COPD: four systematic reviews of the research findings	Yes (GPs prescription in GPRD)
Thromboprophylaxis in medical patients	No
Thrombolytic and neuroprotective therapy for acute ischemic stroke	No
New and old drugs for Parkinson's disease	Yes
Population screening policy for the drug treatment of high blood pressure	No
Screening for stroke	No
Universal antenatal HIV testing	No
Serum, urine, and ultrasound screening	No
Screening practice for Down's syndrome	No
Neonatal screening in the detection of congenital hearing impairment	No
Ultrasound screening during pregnancy	Yes (St. Mary's Maternity Information System)
Screening for cystic fibrosis	No
Hemoglobinopathy	No
Screening for fragile X syndrome	No
Neonatal metabolic screening	No
Systematic review of neonatal screening for inborn errors of metabolism	No
Preschool vision screening	No
Screening for language delay	No

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Table 2. Conitnued

HTA topic titles	HTA identifiable in a routine database
Child health surveillance	No
Screening for ovarian cancer	No
Early screening for hearing disability	No
Screening for hypercholesterolemia versus case finding for familial hypercholesterolemia	No
Screening for *H. pylori*	No
Treatment for localized prostate cancer	No
Targeted screening versus systematic population screening for atrial fibrillation in the over 65s	No
HPV testing in the cervical screening program	No
Interdisciplinary team care for stroke	No
Counseling, CBT, and GP care for depression in general practice	No
Counseling with patients with chronic depression and anxiety	No
Primary care emergency centres	No
The community provision of hearing aids	No
Counseling: an evaluation of complementary interventions	No
Technologies for the diagnosis & monitoring of osteoporosis	No
Postnatal midwifery support	No
Protocol-based, midwifery-led care	No
The use of laxatives in the elderly	No
Health visitor domiciliary visiting	No
Primary care–based patient education program for osteoarthritis of the knee	No
Intensive physiotherapy vs. a home-based exercise treatment program in knee osteoarthritis	No
Physiotherapy for children less than 3 years old with cerebral palsy	No
'Exercise on prescription'	No
Alternative strategies of providing support for socially disadvantaged inner city families with infants	No
Discharge arrangements for older people	No
Brief psychological treatments used in primary care	No
Minor surgery in primary and secondary care	No
Long-term hypnotic drug use	No
Leisure center–based exercise on prescription, home-based walking, and usual advice in primary care	No
Health promotion in schools	No
Self-help guidebook and patient-centerd consultations in inflammatory bowel disease	No
Venous leg ulcers	No
Cognitive behavioral therapy versus antispasmodic therapy for irritable bowel syndrome in primary care	Partial (GP's prescriptions only in GPRD)
Acupuncture in chronic low back pain	No
Acupuncture for migraine and headache in primary care	No
Day care for people with severe mental disorders	No
Best place care for elderly people after acute and during subacute illness	No
Diabetes education interventions for adolescents	No
Interventions to promote the uptake of breast-feeding	No
Home treatment compared with admission for mental health	No
Fluoxetine and cognitive-behavioral therapy versus fluoxetine alone in adolescents with persistent major depression	No
Adolescent anorexia nervosa	No
Problem-solving by community psychiatric nurses (CPNs) for anxiety, depression, and life difficulties among general practice patients	No
Different models of pediatric home care	No

HTA, health technology assessment; D&I, debridement and irrigation; MRI, magnetic resonance imaging; CT, computed tomography; CMV, cytomegalovirus; PET, positron emission tomography; NHS, National Health Service; GPRD, General Practice Research Database; GP, general practitioner; COPD, chronic obstructive pulmonary disease; HPV, human papilloma virus; CBT, cognitive behavior therapy.

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of the underlying data but also by the lack of detail in most standard coding definitions. ICD does not cover disease severity, and in practice, many conditions are coded as unspecified, whereas procedure codes (such as OPCS) specify surgical interventions, detail is lacking on the specific technology used. Furthermore, standard classification systems are very poor at identifying new technologies. There is always a lag before new diseases and procedures, the very ones one might wish to evaluate, are recognized. For example, coronary stenting is not picked up as a technology distinct from percutaneous transluminal angioplasty, and even when eventually it is, it is unlikely that drug-eluting stents will be classed as a distinct technology. Furthermore, no systems exist at all for outpatients, for diagnostic and imaging technologies, or for the range of types of contact in primary and community health services of the organization of health-care delivery.

Fourth, confidentiality presents a new challenge. Data on the use of certain health services have long been deliberately anonymized (returns for sexually transmitted diseases, for example) to prevent stigmatization and encourage uptake. Now, increased legal protection of the privacy of individuals has raised major issues around all health-care records and the degree to which consent is required before data can be entered.

Fifth, there is a vicious circle of quality of data and their use. The perceived lack of value of most NHS administrative databases, which creates a barrier to their use and, therefore, creates a barrier to their improvement.

The coding problem in particular is highlighted by our findings on the "potential use" of routine databases. Very few of the UK's HTA priorities could be identified in routine data. However, we have no reason to feel confident that, had the technologies been coded, the level of patient detail (before and after use) would have been satisfactory in any but those relatively specialized clinical registries that carefully collect patient baseline condition and outcome, and in those where the outcome is relatively stark (e.g., a successful pregnancy, a death, or a population screening program uptake rate).

So, do routine databases hold out any hope for the deficit in information on the effectiveness of health care? Are we entirely limited to randomized trials? There are some signs of hope, but these findings may not be sufficient to change the current pattern of use. Some of the health technology databases we found, that is, the HFEA's data set and the National Transplant Database, for example, have found selective value. The Hospital Episode Statistics have been used to explore variations in clinical outcomes, even if seldom linked to specific interventions. Linked routine data in Scotland, when validated, notably as part of the West of Scotland Coronary Prevention Study Group prospective trial of statins, proved as useful as reporting based on direct patient contact (29). Routine data have also been central to analyses of inequity in health care, and routine data are clearly central to analyses of the diffusion of health technology. The use of routine data has also found some success overseas. In the United States, the patient outcome research teams (PORT) studies (30) used administrative claims data to assess the effectiveness of a range of common treatments, although they have been criticized (25) for potential bias. Sweden has over forty quality registers (20), which include patient specific data on diagnoses, medical interventions, and outcome. Denmark has developed standards for use of its biobank, defined as all health-related databases that include personal identifiers (28), and Iceland provides an example of an attempt to develop a single computerized database linking medical records, family trees, and assorted genetic information.

Information Technology, in health care as elsewhere, offers the potential for major change. Some services, such as intensive care units, are collecting routine data electronically with much greater levels of detail than hitherto. Computerization, unique patient identifiers and linkage between data sets offer the prospect of improvements. They make it increasingly possible to chart patients' complex itineraries through health-care systems, provided the appropriate detail has been captured and coded. Against this background, issues around confidentiality of health-care data are working to diminish their use in health services research (24). Issues of confidentiality, coding, and the use of routine data all need addressing urgently.

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