Review of resource-use measures in UK economic evaluations

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Background

Economic evaluations in clinical trials employ a range of approaches for estimating patients' use of healthcare and other resources. These include: abstraction of data from routine medical records (e.g. patient notes, electronic medical records), use of dedicated sections within case report forms, and questionnaires (or diaries or logs (Marques et al., 2013)) for patients, healthcare professionals, researchers, or informal carers to complete (Figure 1) (Johnston et al., 1999, Evans et al., 2000). A review of trial-based economic evaluations found a widespread dependence on patient recall for resource-use estimation in the UK (Ridyard et al., 2010).

Investigation and review of resource-use measures based on patient recall led to the establishment of DIRUM, the Database of Instruments for Resource-Use Measurement (<u>www.DIRUM.org</u>) (Ridyard et al., 2012). Instruments within DIRUM are catalogued according to: type (diary, recall questionnaire or log); person responsible for completion (patient, patient/carer, healthcare professional, researcher, other); and the method of administration (in person, via telephone, via computer, via post, other). Categories of resources are broadly classified according to primary and secondary healthcare, social services, criminal justice, patient-incurred, and informal care.

A principal aim of DIRUM is to facilitate improvement in the design and development of resource-use measures through open-access to existing measures, challenging current practice regarding the reliability and validity of measurement and establishing guidance for best practice. Central to achieving this is the aim of the present study, which is to systematically define the characteristics of resource-use measures, in relation to the following objectives:

Which resource-use measures, if any, are commonly used? How are resource-use measures administered? Which items of resource-use were mostly measured using patient self-report?

- How does the use of measures differ according to the availability of alternative methods?
- How do estimates compare when more than one method is used for the estimation of the same resource items?

Methods

Overview

A review was conducted of papers that cited publications reporting the use of resource-use measures catalogued in the DIRUM database. From each included article, data were extracted on pertinent characteristics relating to how and what resource-use data were measured, and on the comparative performance of alternative methods of resource-use estimation.

Review

Papers citing DIRUM-listed resource-use measures were identified using search engines which allow for citation searches, namely: Google Scholar, ISI Web of Science and Scopus.

After removal of duplicates, all citations were screened independently by two reviewers and considered eligible for inclusion. Articles were excluded if they were: (i) not a cost or economic study; (ii) lacked a primary analysis; (iii) not published in a peer-reviewed journal; (iv) a review, a book, protocol, thesis or dissertation; (v) not conducted in a UK setting; or (vi) a duplicate publication of the same cohort. Any review articles were screened for additional citations that might be relevant to the DIRUM references.

Data were extracted from DIRUM references and the identified citations, on the: (i) study cost perspective; (ii) methods of data collection for estimating resource-use; (iii) source of the resource-use data; (iv) categories of resources; (v) rates of return of postal questionnaires, (vi) questionnaire completion rates (e.g. for face-to-face or telephone administration); and (vii) correlation among different methods of resource-use measurement, where reported. The number of times the DIRUM

references were cited was recorded, as was whether the resource-use measures described in the citing references were used as originally intended.

Extracted data were tabulated and results described narratively.

Results

At the time of searching, DIRUM listed 38 resource-use measures; however, two were non-UK questionnaires and 11 instruments were either a diary/questionnaire used alongside an existing questionnaire or not published in a citable format, and were excluded. Of the remaining 25 included measures, 23 were questionnaires, one was a diary and one was a log.

Citation searches of these 25 measures yielded 1503 articles (after removal of duplicates) for screening. Application of the selection criteria resulted in 1357 being excluded (Figure 2). Nearly all included citations (143/146) reported Jennifer Beecham and Martin Knapp's Client Service Receipt Inventory (CSRI), or a variation thereof (Beecham et al., 1990, 1999). The other three citations were based on the Annotated Cost Questionnaire (Wordsworth et al., 2001). (A tabulated list of references indicating their main properties is presented in Appendix 1 in the online copy).

Most of the instruments included relied on patient recall (93/146) and were generally administered during researcher interviews (64/93) or completed by the patient themselves (19/93). None of the instruments were reported explicitly as being logs or diaries; however, one questionnaire was reported to have been administered alongside a diary. Among these 93 instruments, the mode of interview was specified in 34 instances and based on the taxonomy for methods of resource-use measurement (Ridyard et al., 2015) were: researcher-completed, face-to-face administered, paper-based questionnaires (23); self-completed, postal-administered, paper-based questionnaires (8); and researcher-completed, telephone-administered, paper-based questionnaires (3). There was variation in the number of questionnaires returned; for example, face-to-face return rates ranged from 51 per cent to 100 per cent in 19 of the 23 studies reporting this; and postal returns ranged from 72 per cent to 89 per cent in six evaluable studies.

Only 37/146 of the studies stated the cost perspective explicitly, but in most cases this could be inferred from the items of resources being measured. The majority adopted an NHS perspective (138/146) and often also included a social services perspective (108). In a few studies, the cost perspective also included indirect costs to employers (18), patients (26) or criminal justice (32) systems.

Among the 93 instruments reliant on patient recall, primary (83) and secondary care (78) were the most widely reported categories of resource-use measured, followed by social services (66), criminal justice (24), accommodation (23), informal care (22), educational (14), patient-incurred costs (12) and lost time at work (10).

Forty-four of the 93 studies supplemented their resource-use measures with other sources of data which included: case notes (27), staff reports (9), computerised administration systems (8) and site finance (2). Where more than one source of information was utilised, it was often unclear what was being reported by the patient and what was being reported by the other source, although case notes were reported as a source of inpatient stays (14/27) and less often for medication usage (2/27).

Twelve studies (among all 146 studies) compared one or more method of data collection for the same resource items (Table 1). Comparisons were generally descriptive, and made between patients' recollection of primary and secondary care services as well as their use of social services, with eight indicating good agreement between medical/provider records and patient/carer recall, and one indicating the greater reliability of case notes. Three were not evaluable.

Where resource-use estimation was not reported to be based on patient recall (53/146), the majority of instruments were administered by researchers or proxies such as patients' relatives (34), with the remainder being unclear as to the source of information. Primary (40/53), secondary (47/53) and social services (38/53) were the most commonly-recorded categories of resource-use in these instances; however, studies in which these instruments were used differed in that case notes were used to a lesser extent (5/53) and hospital finance departments to a greater extent (12/53) than in studies which used resource-use questionnaires reliant on patient recall.

Discussion

The review highlights the extensive use of the CSRI, and variations thereof, to estimate resource-use in economic evaluations in health and social care. Originally designed for mental health service evaluations, the CSRI collects retrospective information about the interviewee's use of health and social care services, accommodation and income. It can be tailored to capture: GP consultations, practice nurse visits, use of hospital services, and contacts with mental health helpline, psychiatric crisis support team, social worker, counselling, therapy, self-help groups and psychiatrist (Beecham et al., 1990; Patel et al., 2005). The review identified applications extending beyond mental health services, ranging from paediatrics to the management of diabetes, suggesting evolution to broader contexts.

Based on the citations of a convenience sample of measures catalogued in DIRUM, it is evident, however, that the reporting of measures is sub-standard, particularly with respect to the methods used. Many did not report the costing perspective, mode of administration, and return or completion rates. A lack of detail in the reporting of resource-use measures may undermine their quality (Ridyard et al., 2015). When details were reported, face-to-face administration was used most frequently and seemed to give higher proportions of questionnaire return than postal or telephone interview. Face-to-face patient interviews may align with responder preference for this method of administration over telephone interviewing (Bowling 2005) and lead to reduced non-response bias compared with mail questionnaires (Evans et al., 2000).

The review has also identified a number of resource-use measures completed by proxies, such as patients' relatives, friends or primary carers. While it is generally agreed patients are the better source of data (Evans et al., 2000), low comprehension, cognitive impairment or ill health in some patient groups may leave researchers little alternative but to rely on proxy report. Levels of concordance between patient and proxy are not well established (Evans et al., 2000).

Primary and secondary healthcare were the most widely-measured resources in studies included in the present review, along with use of social services. Informal care, patient-incurred costs, indirect costs (such as productivity losses), educational and criminal justice costs also featured, but to a lesser extent. Consistent with previous findings (Ridyard et al., 2010) was the large number of studies which supplemented data based on patient recall with alternative data sources, such as hospital records and general practitioner notes. Where more than one source of information was utilised, however, it was generally unclear what was being reported by the patient and what was being reported by the other source, although case notes were sometimes reported as a source of inpatient stays.

Data derived from patients are prone to recall bias and raise legitimate concerns about accuracy (Jessep et al., 2009; McCrone et al., 2007; Slade et al., 2006). Even for memorable events such as hospitalisations, recall periods in excess of 12 months are generally not recommended (Bhandari et al., 2006), with many resource-use questionnaires restricted to a maximum three month recall period (Ridyard et al., 2012). Among studies that compared different methods of resourceuse estimation in the present review, there was indication of good correlation between medical records and patient or carer recall (Patel et al., 2004; Patel et al., 2005; Byford et al., 2007; Sleed et al., 2005; Harrison-Read et al., 2002; Merson et al., 1996; McCullagh et al., 2005; Lang et al., 1997). What was not immediately clear from the study was how estimates based on patient or carer questionnaires compared with other sources in relation to education, social services and criminal justice.

The main strengths of the present study is the systematic identification and assessment of measures catalogued in DIRUM. As such, it represents an overview of the state of the art in the methods of resource-use measurement. There are weaknesses, however, particularly with respect to sampling bias, as resource-use measures catalogued in DIRUM may not be representative of others. However, the findings are consistent with other reviews which focused on studies funded by the UK Health Technology Assessment Programme (Ridyard et al., 2010), and resource-use measures for older people (Martin et al., 2012).

In conclusion, this review highlights the widespread use of the CSRI, and indicates resource-use questionnaires are most commonly employed for estimating patients' use of primary, secondary and social care. These are sometimes supplemented by data extracted from patient records such as GP and hospital notes, although with the possible exception of inpatient stays, the rationale for the selection and use of complementary approaches are not reported reliably. The review suggests that face-to-face interview with patients may result in less missing data than telephone interview or postal administration and, while there are concerns about recall bias, where presented, studies indicated good agreement with medical records.

Table 1: Summary of studies that compare resource-use based on patient (or carer) recall, with other sources of data

Paper	Research context (number of patients)	Method of questionnaire administration (completion rate)	Resource-use categories	Other methods of resource-use measurement	Data collection comparator
Patel et al., 2004	RCT of training care givers of stroke patients including cost- effectiveness analysis, societal perspective, health, social care and informal care; (N=300)	Patient/carer interview; (300/300)	Primary and secondary care, social services, accommodation and informal care	Hospital records for lengths of stay, social services records	Researchers verified the completeness and accuracy of data on use of resources of hospital and social services against records of service providers. No quantitative data reported on the comparison.
Afuwape et al., 2006	Ethnic differences among a community cohort of individuals with dual diagnosis in South London; (N=213)	Client interview; (146/213)	Primary and secondary care, and police contacts	Case notes and case manager interview	Case notes and case manager interview were compared with responses from clients and used as main source of data if client interview not undertaken. No comment on accuracy of questionnaire and no quantitative data reported on the comparison.
Fitzpatrick et al., 2004	The determinants and effect of shared care on patient outcomes and psychiatric admissions - an inner-city primary care cohort study; (N=349)	Patient self-report but unclear if this was during or prior to face-to-face interviews at baseline (349/349) and 12-month follow-up (n= 281/349)	Psychiatric admissions	Protechnic and PsyMon databases held by the local NHS Trust	Resource-use questionnaire and database outputs cross- checked, no comment on accuracy of questionnaire and no quantitative data reported on the comparison.
Byford et al., 2007	RCT data, comparison of alternative methods of collection of service use data for the economic evaluation of health care interventions for people who self-harm, broad multi-agency perspective inclusion of accommodation; (N=480)	Participant interview, (CSRI data 397/480, GP record data 272/480)	Primary and secondary care	GP records (including inpatient, outpatient, day hospital, A&E, GP, practice nurse)	GP records used to compare with patient recall for health contacts. Agreement was high for GP (Lin's coefficient 0.631), A&E (0.760) attendances and total inpatient days (0.658). Authors concluded GP records appear to provide more accurate information than patient report on contacts with GPs and practice nurses, but less reliable information on contacts with other health services.

Paper	Research context (number of patients)	Method of questionnaire administration (completion rate)	Resource-use categories	Other methods of resource-use measurement	Data collection comparator
Patel et al., 2005	A comparison of GP data and patient recall of collecting economic data in primary care; (N=303)	Self-completion postal questionnaire based on patient recall (229/303)	Primary and secondary care, social services	GP records	Authors concluded that there is good agreement between the number of GP visits recorded on GP case records (mean 3.03) and on the CSRI (mean 2.99) (concordance correlation coefficient 0.756).
Lam et al., 2005	Cost-effectiveness of relapse-prevention cognitive therapy for bipolar disorder: health service perspective; (N=103)	Face-to-face administered questionnaire with participant every 3 months; data available for 83/103 for 0-30 months	Primary and secondary care, social services, accommodation	Hospital computerised records	Hospital computerised records were used to confirm the exact length of hospital stays. Use of self-report alone was noted as being potentially limiting where accuracy was concerned. No quantitative data reported on comparison.
Sleed et al., 2005	The economic impact of chronic pain in adolescence: methodological considerations and a preliminary costs-of- illness study; (N=52)	Postal questionnaire for parental completion (but also used in face-to-face and telephone interview format during development); (52/52)	Primary and secondary care, education, time off work, informal care, out- of-pocket expenses	Hospital records	Hospital records corresponded well with parental recall measure, but the latter judged to be better as it also measured resources outside of hospital. Authors concluded that reliance on medical records would have greatly underestimated patients' service use. No quantitative data reported on the comparison.
Harrison-Read et al., 2002	RCT of enhanced community management in an outer-London borough; cost study, NHS & social care perspective; study group; (N=193)	Patient interview; (125/193)	Primary and secondary care	Patient computerised records	Patient computerised records were used to informally validate interview data and stated to show similar patterns to the reported costs. No quantitative data reported on the comparison.
Merson et al., 1996	RCT of the cost of treatment of psychiatric emergencies: comparing allocation to hospital or community services; (N=100)	Patient assessment interview; (95/100)	Primary and secondary care, social services, police and probation	Clinical records	Clinical records used to verify service use data collected but no quantitative data reported on the comparison

Paper	Research context (number of patients)	Method of questionnaire administration (completion rate)	Resource-use categories	Other methods of resource-use measurement	Data collection comparator
McCullagh et al., 2005	RCT of care-giving and QoL in carers of stroke patients; no economic analysis or costs; (N=300)	Patient interview; (232/300)	Primary and secondary care, social services	Records of service providers	The completeness and accuracy of data obtained via patient interview were reportedly verified against records of service providers but no quantitative data reported on the outcome.
Lang et al., 1997	Cohort study, Service provision for people with schizophrenia: NHS, social care, informal care perspective; (N=311)	Face-to-face administered questionnaire with 166 patients and carers; (131/166)	Primary and secondary care, social services, accommodation, adult education	Demographic and treatment data from patient record	The information given by the patients on their use of services was verified by referring to the service contacts recorded in their case notes. No quantitative data reported on the outcome.
McCrone et al., 2009	The REACT Study: Cost- Effectiveness Analysis of Assertive Community Treatment in North London; (N=251)	Patient interview; (166/251)	Primary and secondary care, social services, accommodation, informal care and criminal justice	Patient case notes	Case notes on inpatient stays and contacts with mental health workers used in preference to responses from patients.





Figure 2: Flow diagram of study selection and inclusion



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