

## Future Directions for DIRUM, the Database of Instruments for Resource Use Measurement

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### Background

In an ideal world, healthcare resource use data needed for health economic analysis alongside randomised controlled trials would be downloaded from readily-accessible databases. Depending on the perspective of the analysis, trial-linked, anonymised information would be easily selected from hospital inpatient, hospital outpatient, general practitioner, social services, national statistics and health insurance datasets. The data would be regularly updated by smooth and seamless interfaces linked to all the input sources. The information gathered would be useful for other applications, too, most notably, local healthcare management, introduction of new working practices, long term validation of new medications, investigating national burdens of care and the never-ending quest for value for money.

For countries like the UK, seamless, researcher-friendly data linkage remains elusive. Countries on the United Nations list of least developed countries experience similar problems, especially where information technology and data capture systems are still under development. Where these technical difficulties arise, healthcare resource use information must be captured by other methods including: patient self-report (e.g. questionnaires, diaries or interviews); use of routinely available data (e.g. medical records); and the use of expert panels or consultants. Each of these methods has advantages and disadvantages. Use of routinely collected data, for instance, depends on accurate recording, the standard of information technology infrastructure where available and more importantly, when written notes and records are used, their language and legibility. Patient self-report (i.e., relying on patient recall) is also useful; however, it can place a cognitive burden on respondents, [1] compelling them to understand the question, recall the requested information, then evaluate and frame a response. Despite these limitations, and probably because of ease of implementation, a quick glance at the UK Health Technology Assessment website will show many trial-based economic evaluations in the UK have relied on patient recall for at least one aspect of data collection [2].

At Bangor University, we quickly realised there were published guidelines and reviews on the conduct of economic evaluations alongside controlled trials [3-5] but no single databases holding a collection of resource use questionnaires. From this we conceived the idea for the Database of Instruments for Resource Use Measurement (DIRUM) [6] and the formation of the DIRUM Team. With funding obtained from the Medical Research Council Network of Hubs for Trial Methodology Research, we set about designing and implementing DIRUM to the point it is now a free-to-use, open-access database of resource use questionnaires. DIRUM also offers a unique (and permanent) web address for each resource use instrument for citation in papers and reports. The database can be accessed on <http://www.dirum.org/>

To date (24<sup>th</sup> January 2019), DIRUM has hosted over 24,000 visits and provided over 7,500 resource use instrument downloads. The most popular instrument for download on the site is the annotated cost

questionnaire for completion by patients [7]; this and 5 other popular downloads [8-12] are outlined in Table 1. Whilst the majority of the user base is in the UK, more than half the visits now come from other countries including Canada, North America and Australia (Table 2).

### What Has DIRUM Achieved to Date?

DIRUM's most useful attribute is how it keeps a large collection of resource use instruments and can serve as a one-stop destination for health economists and other researchers trying to work out what important items of healthcare resource use need to be considered when setting up new controlled trials. Other benefits of DIRUM include a permanent link to resource use questionnaires for researchers when reporting their trial protocols and a list of methodological papers relating to resource use measurement. More recently, DIRUM has helped generate a nomenclature system for resource use instruments, [13] naming them in the context of the data source (e.g. from patient, proxy, medical records or other databases); who completes the instrument (e.g. patient or their proxy, researcher or healthcare professional); how the instrument is administered (e.g. self-administered, face-to-face, telephone, on-line); type of instrument (e.g. form, questionnaire, log, diary); and the medium of recording (e.g. pen & paper, electronic, mobile devices, computers). Instruments from DIRUM were also involved in a recent project to identify a set of economically-important core items for a standardised resource use measure (the ISRUM study) [14]. The study aim was to assess similarities and differences between the instruments in DIRUM, extract a list of potential resource use items and conduct a Delphi Survey to achieve a consensus opinion on which of these items should be included in a generic instrument for resource use measurement. Health economists with experience of working on trials in the UK were recruited to an expert Delphi panel via an email to the UK Health Economists' Study Group (HESG) mailing list. They were asked to rate 60 key resource use items on a scale from 1 to 9 according to how important they felt the item was in a generic context. Over 40 health economists took part in the survey and reduced the list of items down to 10, which they believed should be present in a generic resource use instrument. Several areas suitable for forming additional bolt-on modules were also identified, such as patient-incurred costs.

### DIRUM's Future

As a repository for resource use instruments, DIRUM is unique.

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Title	Disease Area	Unique Downloads	Reference
An annotated cost questionnaire for completion by patients	Generic	623	Wordsworth et al. [7]
Client Service Receipt Inventory	Generic	257	Beecham & Knapp [8]
ANCHoR Questionnaire	Cancer	227	Molassiotis et al. [9]
CFS Self-Report Questionnaire	Chronic Fatigue Syndrome	175	O'Dowd et al. [10]
Self-Report Questionnaire for use of health and social service (used in AHEAD Trial)	Depression	172	Peveler et al. [11]
AESOPS Questionnaire	Heart & Circulation	168	Watson et al. [12]

**Table 1:** The top 6 resource use instruments downloaded from the DIRUM database.

Country	Visits	%Total visits	Pages per visit
United Kingdom	1425	38.3	4.96
United States	361	9.70	2.68
France	237	6.37	1.48
Australia	213	5.72	3.84
Germany	117	3.36	2.98
Netherlands	125	3.65	4.94

**Table 2:** Top 6 countries for DIRUM visits in 12 months prior to October 2018.

For the foreseeable future, we will continue to accept resource use instruments from any part of the world and in any language providing there is an English translation accompanying them. Database users are encouraged to submit and report on their own use of DIRUM instruments, too. We always welcome user experience on test-retest, intraobserver, interobserver and alternate-form studies to strengthen instrument reliability. Just as importantly, we welcome reports on any face, content, criterion or construct validity studies. An exciting development underway in the DIRUM pipeline is to make the database a repository for health economic analysis plans (HEAPs). Initial systematic reviews are already underway exploring this new direction and we hope to publicise this further in the coming months. There is further future development potential for DIRUM as a dynamic platform to assist troubleshooting and problem solving in hospitals and clinics. Modernisation teams in the UK National Health Service for example often need to measure resource use and ensure new infrastructure, innovation and interventions offer value for money without transferring the burden of cost elsewhere. Since DIRUM has many of the necessary ingredients in place already this could provide a natural evolutionary pathway for further database growth.

Since the database has expanded, we have received instruments not just on clinical trials but also on measuring the financial health burden experienced by people in developing nations, e.g. Cambodia [15] and Kenya [16]. Both countries experience their own unique challenges (e.g. transport and infrastructure); however, their common denominator is severe illness puts a considerable financial strain on families because they have to meet the bulk of total health expenditure with limited means. A potential longer-term contribution DIRUM can make is to assist local health care professionals in devising effective questionnaires for measuring financial burden. This could help to better understand the healthcare needs of often widely-distributed populations with disparate cultures, and allocate limited resources more effectively. With overseas development comes a need to open up new avenues in the database, especially with respect to translation. More than half of DIRUM's internet traffic now comes from outside the UK, meaning there is potential for translating some of the resource use measures already present into other languages. George Bernard Shaw once said: "We are made wise not by the recollection of our past, but by the responsibility for our future"; perhaps with DIRUM we can

now rephrase that and say: "Recollecting our past healthcare resource use means we can allocate our future healthcare resources more wisely and responsibly".

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