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, 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 address these limitations. Now 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].

DIRUM's Future

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

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but by the responsibility for our future”; perhaps with DIRUM we can 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”.

References