



Exploring the prospect of a complementary and integrative medicine database for use in the Australian primary care setting



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ABSTRACT

Background: A minimum dataset (MDS) has the potential for many uses in the complementary and integrative medicine (CIM) setting. Methods such as comparative effectiveness (CER) are conducted in real-life clinical settings using data sourced from clinical records and patient reported outcomes (PROs), which is then collated into a MDS of high quality to provide information both immediately and over time. Other uses of a CIM-MDS include surveillance and monitoring CIM use.

Method: Strategies for establishing a CIM-MDS in Australia were explored. The focus was data sources, especially the role of PROs. The findings drew on a body of research that included a case study of an IM primary care clinic; interviews with patients, practitioners, and staff from the clinic and a systematic literature review of patient questionnaires for use in the IM setting.

Results: Aside from basic information, automated data extraction of clinical data from Australian CIM clinics is very limited. A small battery of patient (and possibly practitioner) questionnaires may be the best way to begin obtaining data. Patient and practitioners may well seek benefits other than contributing to research from the exercise of data collection, such as accessing individual patient results to track outcomes and inform clinical care. The format of the questionnaires matters as well. Although electronic formats are acceptable to many patients, paper questionnaires are still preferable to some.

Discussion: A bottom-up approach that involves all stakeholders and builds on other national and international initiatives is recommended for developing a CIM-MDS. The final choice of data for a CIM-MDS will be informed by its intended uses. The lack of any standardised nomenclature for CIM coding is an important obstacle to building a robust dataset; however, in establishing a CIM-MDS there is the opportunity to collect data that could help inform a CIM coding system.

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What is already known about the topic

- Health services and researchers use minimum datasets for surveillance and research.
- Health service dataset and national data networks are proposed for use in comparative effectiveness research.
- Most of the data relevant to CIM are not included in sufficient detail in existing or proposed datasets for CIM research.
- A bottom-up approach that involves all stakeholders is recommended when building such a dataset.

What this paper adds

- CIM would benefit from establishing a minimum dataset, both in Australia and internationally.

- Newer methodological and analytical approaches could address some of the complexities of evaluating CIM.
- A dataset that predominantly uses patient reported outcomes questionnaires is recommended for the Australian setting.
- The challenges of creating a CIM minimum dataset in the Australian primary care are discussed.

1. Background

The National Institute of Complementary Medicine, Australia recommended the development of a complementary and integrative medicine minimum dataset (CIM-MDS) [1]. This paper draws on a body of work undertaken in response to the recommendation [2–8]. CIM is an evolving term, for the purposes of this paper it is used broadly and refers to traditional, complementary and alternative medicine used in isolation or integrated with Western biomedicine.

A minimum dataset (MDS) is an agreed core set of data. Generally, these data are then collected in a standardised way from

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one or many sources and over time. Common uses of a MDS by healthcare-related organisations encompass research, surveillance, health service monitoring, and evaluating clinical outcomes and quality of healthcare [9]. A recent CIM example was the use of healthcare registries in Sweden that compared mortality and drug prescription patterns of patients using anthroposophic integrative care and conventional care for pain and stress disorders [10].

The uses and complexity of datasets are increasing as more data are collected electronically. However, many datasets are still to reach their full potential for evaluating clinical outcomes and effectiveness and most do not measure many of the outcomes relevant to CIM [4,11]. For example, in the UK, the Clinical Practice Research Datalink extracts data from the primary care electronic health records (EHR) for linkage with other surveillance datasets [12]. The stated aim is to “support clinical innovation, strengthen evidence of effectiveness and improve health outcomes as well as safeguard public health and enable health services research” [13]. Patient reported outcomes that are important outcomes for CIM are not routinely collected, which will limit its usefulness in CIM effectiveness research. Furthermore, many CIM healthcare activities are not recorded.

The Patient Centered Outcomes Research Institute in the USA has recently set out to support clinical effectiveness research by establishing a national research network with the aim of linking data from health services and other sources, including patient advocacy groups [14]. Given the focus will by necessity remain on linking data that is relevant to the dominant biomedical health services, for the foreseeable future, it is unlikely the research network will collect data that can answer many of the CIM effectiveness research questions.

In Australia, the majority of primary care physicians and hospitals use EHRs [15]. However, the precise number is not known and there is no information available for CIM practitioners. Similar to the UK and USA, data collection by Australian health services remains ad-hoc and uncoordinated, especially in primary care where there are less funding requirements to systematically collect and code data [15,16]. In 2012, the Australian Government launched the national personally controlled e-health records system. Deciding what data to include, who will enter and maintain the data, who will have access to the data and data security stand as serious operational questions [17]. SNOMED CT [18] is the coding system that will be used to standardise data collection from primary and secondary care health services, but it does not code for many CIM activities.

Patient generated datasets are increasingly perceived as an important source of health data. An example is the website ‘Patients-like-me’ that is a forum where people enter data about their demographics, health profile, treatments and outcomes. Members can share personal experiences with others who have the same diagnosis, track their personal data over time and review longitudinal aggregate data [19]. A novel use of the data was an algorithm matched case–control effectiveness study investigating the outcomes of an off-label use of a prescription medication [20]. The dataset aims to collect detailed information about the use of pharmaceutical medications and biomedical interventions. This is achieved by providing drop down menus that enable patients to easily enter this data. In contrast, the majority of CIM therapies and interventions must be manually entered. The website has also started using standardised PRO questionnaires that patients use to track their progress and compare themselves to others.

The potential applications of a purpose built CIM-MDS include monitoring CIM use, safety and acceptability and evaluating CIM outcomes. A CIM-MDS could also help reduce the costs of research projects and promote multi-centre research. Observational studies that use longitudinal data will obviously benefit from the use of a CIM-MDS that could include quasi-experimental designs such as

comparative studies of matched pairs sourced from the longitudinal data [21]. The observational data could also be used to flag potentially effective therapeutic approaches for further evaluation using more rigorous study designs and identify potential safety issues.

Evaluating CIM is challenging because the interventions and outcomes are complex, broad and context-specific [22]. Mixed methods, comparative effectiveness research, observational outcomes research and whole systems research are recommended CIM methods [21,23–26]. All of these approaches would benefit from accessing data collected through a CIM-MDS.

Comparative effectiveness research (CER) is enjoying new popularity, especially in the US where a wide range of experimental study designs are proposed. CER based in primary care practice has also been recommended for CIM research [27]. The clinically integrated randomised trial is an example of the CER approach that aims both to measure effectiveness and enhance the generalisability of the results [28]. It uses data already collected by a health service dataset. No extra information is collected from the participating patients, so any PROs must be collected as a part of routine clinical care. This method helps to ensure that the experience of treatment allocation and observation for those in the trial and for their treating practitioners are similar to those not participating in the trial. The main inclusion criteria are the practitioner is uncertain about which therapy would be best for their patient and there is no preference for one therapy over another. A therapy is then randomly allocated to the pre-consented patient. Ideally, the patient and practitioner are blinded. IM would be well suited to this approach to research because often there are a variety of management options from which practitioners can choose and limited information about their comparative effectiveness.

Large datasets offer other possibilities for data analysis that are congruent with the philosophy of CIM. Advances in computing power and inferential statistics have the potential to analyse the complexity of CIM in a much more holistic way that is individualised, patient-centred and multidimensional. Multilevel analysis (MLA) can be used to explore how the different levels of patient, therapies, practitioners, clinical settings, and social and geographical circumstances interact to influence patient outcomes. MLA reduces the risk of generating misleading results from statistical and conceptual errors that can occur when data from different levels are analysed on the same level [29]. Aickins proposes similar statistical methods for use in CIM comparative research that aim to deal with the statistical challenges of analysing consecutive measurements and multiple outcome variables. Called Participant-Centered Analysis, these methods can be used to analyse within-patient data to provide valid information about individual patient outcomes [30].

The intended uses of CIM-MDS will govern the types of data needed. If CER was an intended use of the CIM-MDS, then the data collected would need to include some information about patient demographics and medical history, the therapies and services used by patients, and objective and subjective patient outcomes. For multilevel analysis, contextual information about practitioners, health services and geographic location would be needed. Example of the types of data that could be collected by a CIM-MDS for research purposes is presented in Table 1.

Patient data could come directly from patients answering questionnaires and indirectly from health services EHRs, personal e-health records and practitioner questionnaires. Patient and practitioner questionnaires could also be used to obtain data about participating practitioners and clinics. Geographical, social and health information could be sourced from health and social service agencies and even private health insurers; it could include census data, population surveys and information about health services.

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