The need for data beyond primary diagnosis

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Information from clinical trials informs our treatment of breast cancer, as it does that of many other common diseases. The trials establish "ideal" management, but the relevance of this information to any individual patient varies because the strict inclusion criteria used for trials exclude many important groups in the community. In breast cancer trials, the old, the poor and the rural-dwelling are often underrepresented. So, the art and challenge of modern medicine centres largely on translating idealised trial data into the best care for our patients.

In this issue of the Journal, Lord and colleagues describe the incidence of metastatic breast cancer in Australian women with an initial diagnosis of non-metastatic disease (*page 688*). This is the first population-based Australian report on this subject, and it provides "real world" data that complement trial statistics, and that will inform discussions with Australian women newly diagnosed with breast cancer, for whom the issue of possible cancer spread is personal and vital.

The article is important for its headline findings, its methods and its implications for clinical care and the collection of meaningful data.

The incidence of metastatic breast cancer, within 5 years of diagnosis, was found to be about 5% for women with localised disease and 18% for women with regional disease at initial diagnosis, with most metastases occurring in the second year. The study could not assess the effect of tumour biology, but it is clear that nodal involvement remains a major determinant of outcome.

That outcomes were worse for younger patients and women from areas of lower socioeconomic status indicates that resources need to be directed towards these (now) proven areas of need.

The study used data from the New South Wales Central Cancer Registry, and through the Centre for Health Record Linkage was able to link the this information with data from the NSW Admitted Patients Data Collection to determine the incidence of metastatic disease. The finding that some patients with metastases may not have been admitted to hospital or have had biopsies (and thus were not recorded in the hospital data or reported to the cancer registry) means that the study may have missed some women.

Clearly, health record linkage is a powerful tool, and it promises much for the elucidation of data that are representative of (and applicable to) the general population. However, that the study by Lord and colleagues was limited by only having information available from hospital and cancer registry sources indicates that there is an important need for accurate and reliable population-level registry data about cancer biology and other possible prognostic factors about cancer treatments, and about cancer recurrence, not just its incidence. In NSW, an additional register called the Clinical Cancer Registry has been established to collect such information. These data will also allow the detection of changing trends in outcomes after the diagnosis of local and regional breast cancer in a more timely fashion than mortality data, given that most women diagnosed with breast cancer can be expected to live for many years. Further, where reductions in deaths are observed, we would be better placed to determine whether this is attributable to a decrease in distant spread or to increases in the duration of postmetastatic survival as a result of improved treatment of metastatic disease. While the development of a clinical cancer registry is an excellent initiative, unfortunately, at this stage, the data collection is limited to public-sector facilities.

It is important that issues surrounding the collection of accurate and comprehensive data and the linkage between registers are well thought out. The legislative hurdles associated with the information sharing that would enable the development of a national clinical register are daunting. However, fragmentation of information is undesirable, and the potential for the e-health record to contribute to the automated collection of high-quality information is clear, and should be a priority.

Electronic health records — are you ready?

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Medicine's elders

As Australia's population ages, demand for geriatricians is set to further increase

In just under 2 weeks, your patients will be able to register for an electronic health record that contains a summary of all their health information. The government says that these personally controlled e-health records will help improve the quality of health care Australians receive — but what does it mean for doctors? In this issue of *MJA Careers*, the Money and Practice section looks at the implications of electronic health records, including the extra work that may be involved for doctors, particularly general practitioners, and the medicolegal implications (*page C7*). Also in this issue, we talk to the medical director of the Australian Olympic Team, Dr Peter Baquie, who will soon be heading to London to provide medical advice to Australia's elite athletes (Road Less Travelled, *page C6*). Dr Baquie's story is certainly a road less travelled: he has gone from being a rural general practitioner to travelling the world with sporting teams.

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