Quality is essential in diabetes disease registers

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O’Mullane and colleagues have reviewed the literature regarding the impact of diabetes registers on the process and outcomes of patient care. This review was conducted as part of a project aimed at establishing the feasibility of a national diabetes register in Ireland. A good starting point for assessing the usefulness of setting up a register is to review the existing evidence regarding effectiveness; the review therefore makes a valid contribution to the overall aims of the feasibility project.

In reviewing the papers identified by their searches, the authors highlight the widely accepted role of disease registers as an integral part of structured patient care. They also draw attention to the difficulty of quantifying the role of such registers in improving patient care due to the fact that, in the studies reviewed, the use of a register was typically just one aspect of the intervention. The authors acknowledge this weakness in the evidence, which stems from a general problem related to complex interventions, namely the difficulty of extracting the contribution of different elements of the intervention. In the studies identified by the review, the authors also found that the interventions were more likely to improve process indicators than to show outcome benefits. Nevertheless, in spite of these limitations, the findings of the review provide general support for the benefits of setting up a diabetes register.

Whilst disease registers are likely to have important benefits for quality assessment and improvement, for research and directly for patient care, this assumption must be qualified by the need for accuracy within such databases. As is the case with any computerised database, the usefulness of a disease register will be limited by the quality of the inputted data. With diabetes there are some specific problems in terms of potential accuracy. Some of these are related to the fact that diabetes mellitus is not a single condition but comprises a range of types, of which type 2 and type 1 are the most common, but my no means the only, classifications.

A study exploring the accuracy of diabetes diagnostic data in two UK databases identified significant numbers of cases of inaccurate data, particularly in relation to the distinction between type 1 and type 2 diabetes. Different types of diabetes require distinct management strategies including prescribing, but differentiating between these types can be difficult and errors can have important implications for patients and other stakeholders. Discrepancies and inadequacies have been highlighted in relation to the ‘picking lists’ for recording a diagnosis of diabetes that are offered on electronic patient record systems in UK primary care; these limitations have been identified as potentially contributing to inconsistent data recording. Ongoing uncertainties regarding the comparative accuracy of different methods of confirming or refuting a diagnosis of diabetes are also likely to compound the problem of inaccuracy within the data available for input into a register.

Whilst the paper by O’Mullane provides support for the usefulness of setting up a national register in Ireland, it is important that this initiative is carried out with an awareness of the importance of assessing the quality of the data that will be entered into that registry and the additional need for a programme designed to improve the quality of the data on an ongoing basis.

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