Refereed paper

Informing the development of a national diabetes register in Ireland: a literature review of the impact of patient registration on diabetes care

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ABSTRACT

Background Research suggests that a structured approach to diabetes care can lead to improved patient outcomes. In order to enable greater organisation of care, an electronic patient registration system is required. As part of the development of a national disease register in Ireland, we conducted a review of literature relating to the impact of registration systems on processes and outcomes of care.

Objective The aim of the review is to establish the impact of a registration system on patient care and clinical outcomes. The review explores the role played by a patient registration system, particularly in the primary care setting.

Methods The literature review applied a search strategy to six identified databases. Included studies were those based on original research, including a patient registration system and published between 1999 and 2009 in the English language. Studies including only patients with type 2 diabetes or those with both type 1 and type 2 diabetes were included.

Findings In interventions of structured care which used a patient registration system, modest results for clinical outcomes were demonstrated as well as significant improvements in the processes of care. A patient register was a necessary step along the path towards improved patient clinical outcomes, notably glycated haemoglobin (HbA1c), blood pressure and cholesterol measurements.

Conclusions This review suggested that registers are generally assumed to be an essential element of quality improvement interventions rather than an optional addition. A diabetes register is central to the development of a comprehensive diabetes management system in primary care, which can lead to improvements in the processes and outcomes of diabetes care.

Keywords: diabetes, family practice, register

Introduction

The Health Research Board (HRB) of the Republic of Ireland has funded a National Diabetes Register Project (NDRP) to examine the feasibility of establishing a national diabetes register.

Diabetes mellitus is a condition associated with poor mortality and morbidity outcomes. Effective treatment and measures for prevention can be implemented to improve these biomedical outcomes. The
Institute of Public Health Ireland has estimated that in 2005 4.7% of all adults in Ireland had diabetes mellitus, and this figure is predicted to increase to 5.6% by 2015. Research has shown that diabetes care provision at primary care level in Ireland is largely unstructured and could be improved with organisational-level interventions. Improved organisation of care might be facilitated and supported by a register and, possibly, by some form of electronic decision support.

Research focused exclusively on the role of patient registration for diabetes mellitus care is limited. Quality improvement interventions tend to be multidimensional. Consequently, studies that reported on the use of a register as part of a wider intervention to improve care were included in this review. Studies which examined electronic medical records (EMRs) and their use within primary care units and in sharing information with other health professionals were also included. All types of electronic data management and sharing systems are likely to contribute to the achievements of the goals of the NDRP.

**Aim of literature review**

Renders et al have suggested that a structured approach to diabetes care provision involving a central computerised system can improve patient outcomes. With this in mind a literature review was conducted to address the relevant questions in relation to the electronic registration of patients with diabetes. These questions include:

- Does patient registration improve care delivery and clinical outcomes for patients with diabetes?
- What is the role of diabetes registration systems in primary care?

**Methods**

Six databases were systematically searched for relevant articles: MEDLINE, CINAHL, EMBASE, the Cochrane Database of Systematic Reviews, LILACS/BBO and ERIC. The search strategy was initially devised for MEDLINE and subsequently amended for the remaining five databases. In total, 754 articles were identified by the searches. After reviewing titles and abstracts, the list was refined. Searching by hand and cross-referencing ensured other relevant studies were included. Six studies were found in this manner. In total, 23 studies were included in this review. The search strategy focused on patients with type 2 diabetes, as this group is principally managed in primary care. Studies that included patients with type 2 diabetes only or with type 1 and type 2 diabetes were included. Some studies were not explicit about the type of diabetes patient included. According to the Cochrane Effective Practice and Organisation of Care Group (EPOC) taxonomy, an electronic patient register is a ‘general electronic medical record system or electronic tracking system for patients with diabetes’. This definition was adopted during the systematic searching of academic journal databases for this review.

**Search strategy**

The search strategy was constructed using a combination of medical subject headings (MeSH) and free-text terms; (Diabetes Mellitus*exp /or Type 2 diabetes); ("Registries/ or register/ or Registr"* /or 'Medical Audit'* /or Practice Guidance/ or Guideline Adherence/ or Medical Records Systems, Computerized/ or Reminder Systems/ or Education/ or Case Management/ or 'delivery of health care' / or disease management*); ('Family Practice/ or family pract.tw./ or Primary Health Care'); (systematic.mp. or "Clinical Trials as topic/ or exp Randomized Controlled Trial* pt / or exp Controlled Clinical Trials* / or Intervention Studies / or Evaluation Studies/ or "Feasibility Studies/ or exp Program Evaluation").

**Inclusion criteria**

Only original research papers, available in full-text format and in the English language, on interventions involving patient registration were included. Articles published between the years 1999 and 2009 were included for review. Editorials and commentaries were excluded.

**Descriptive overview of studies**

**Systematic reviews**

Five systematic reviews were identified as relevant. Two systematic reviews were extracted from the Cochrane Database of Systematic Reviews. Griffin and Kinmonth examined the effects of involving primary care in the routine review and surveillance of patients with diabetes. The review concluded that prompted general practice care for uncomplicated diabetes can be as good as or better than hospital care. The authors concluded that registration, recall and regular review
are necessary to advance the quality improvement of diabetes care. Renders et al reviewed interventions that sought to improve the management of diabetes in primary care, outpatient and community settings. The most relevant point in relation to patient registration was that care needs to be more structured and that centralised computer systems can aid this endeavour. Renders et al concluded that multifaceted interventions can improve the management of diabetes, as can organisational interventions that improve recall and involve central computerised tracking of patients.

A systematic review assessed the quality of morbidity coding in computerised general practice records. The study highlighted the numerous problems faced when coding, such as the lack of standardised coding methods. ‘Whole-of-practice’ training is suggested for a reasonable standard in coding.

One study used meta-analysis to examine the effect of quality improvement strategies exclusively on clinical outcomes. Shojania et al examined the impact of 11 quality improvement strategies on glycaemic control in patients. Eight trials included an electronic patient register which after pooled analysis was associated with an effect on post-intervention glycated haemoglobin (HbA1c) of 0.4% relative to control groups in the included studies. Across all 66 trials, after adjustment for relevant confounders, only two strategies were associated with reductions in HbA1c of at least 0.5%; team changes and case management.

Joshy and Simmons highlighted the critical success factors for the establishment of diabetes information systems. They noted that electronic linkage between primary care systems and hospital systems was necessary in order to eliminate delay in information update on patients and to provide necessary clinical information and results at the point of care.

Randomised controlled trials

Five published trials relevant to this review were identified. All studies examined the processes of care and outcome measures. Although improvements in processes of care were found, the trend for significant improvement in clinical outcomes was modest. The organisation of care was enabled by the inclusion of an electronic register in the practices, but the translation of this into improvements in clinical outcomes was not easily identifiable. It is difficult to establish the impact of the computerised register when there are other strategies within an intervention at play, as the register is not the only variable being evaluated for the quality improvement of care and outcomes.

The studies also suggested that the relatively short time span of the interventions could explain the modest improvement in clinical patient outcomes. The mean average of trial duration was 21 months for the five randomised controlled trials (RCTs).

In these studies the register played a crucial (albeit supporting) role in quality improvement. This was a common trait within the included RCTs. It is assumed to be a ‘backbone’ feature for diabetes management programmes, without requiring justification or qualification of its place in the interventions. That is to say, a diabetes register is taken for granted in programmes that seek to improve the quality of diabetes care management.

Research examining diabetes management and registration

A number of non-controlled intervention studies were also included in this paper. Overall, the studies concluded that a patient registration system, alongside other quality improvement initiatives such as continuing education, government policy encouraging registration and audit, was a necessary ingredient for a comprehensive management system.

Most of the studies outlined below found improvements in processes and outcomes. Typically a register was just one component of the intervention rather than the sole focus. A register formed part of all interventions and studies, whether as the sole focus of the study (Pollard et al) or as a minor role in the intervention (Goldfracht et al). This demonstrates the important role that registers play in diabetes management research. Processes of care and clinical outcomes were measured in 18 of 23 studies (Table 1) so as to assess patient care and improvement. A register played a role in enabling this examination. This indicates the integral, albeit indirect role that patient registration systems play in diabetes management.

Studies included in the review were conducted in various countries around the world. One study examined three district registers in Australia and compared their processes and outcomes; a study, based in the Umbria region of Italy evaluated a register system devised within a region and across healthcare settings; one study used a central register to report on the process and outcome measures for improved diabetes care with a random sample of patients in Israel; and a patient register for comprehensive screening for diabetic retinopathy in North Wales was used in order to examine whether population-based retinopathy screening, using a central diabetes register and screening methods, could achieve population coverage.

Modest improvements were also demonstrated in the RCTs included in this review. The Vermont Diabetes Information System project found improved patient testing (processes) without changed clinical
<table>
<thead>
<tr>
<th>Author/year</th>
<th>Type of intervention study/methods used</th>
<th>Study aims</th>
<th>Processes of care and clinical outcomes measured</th>
<th>Patient studied&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Type of diabetes of patients studied (if applicable)</th>
<th>Physician studied&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Location</th>
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<tbody>
<tr>
<td>MacLean &lt;em&gt;et al&lt;/em&gt; 2009&lt;sup&gt;15&lt;/sup&gt;</td>
<td>RCT</td>
<td>To evaluate the impact of a registry and decision support system (DSS) on processes of care and physiological control</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>USA</td>
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<tr>
<td>Harvey &lt;em&gt;et al&lt;/em&gt; 2006&lt;sup&gt;20&lt;/sup&gt;</td>
<td>Screening intervention programme using central diabetes register</td>
<td>To examine whether population-based retinopathy screening using a central diabetes register and employing various screening methods can achieve a high degree of population coverage to meet National Screening Committee (NSC) targets</td>
<td>No</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>Wales</td>
</tr>
<tr>
<td>Goldfracht &lt;em&gt;et al&lt;/em&gt; 2005&lt;sup&gt;17&lt;/sup&gt;</td>
<td>Intervention involves reporting the results of a review of patient measures</td>
<td>To improve the diagnosis of diabetes in the community and improving the follow-up of diabetes patients in primary care (achieved this, next stage is to improve glycaemic control)</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>Israel</td>
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<tr>
<td>Jordan &lt;em&gt;et al&lt;/em&gt; 2004&lt;sup&gt;9&lt;/sup&gt;</td>
<td>Systematic review</td>
<td>To assess the quality, in terms of completeness and correctness, of morbidity coding in computerised GP records through a systematic review</td>
<td>Yes</td>
<td>No</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>UK</td>
</tr>
<tr>
<td>Griffin and Kinmonth 2000&lt;sup&gt;7&lt;/sup&gt;</td>
<td>Systematic review</td>
<td>To assess the effects of involving PC professionals in the routine review and surveillance for complications of people with established DM compared with secondary care specialist follow-up</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>No restriction on location (COCHRANE)</td>
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Table 1 Continued

<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Study Design/Methods</th>
<th>Study Aim</th>
<th>Type</th>
<th>Yes/No</th>
<th>Yes/No</th>
<th>Yes/No</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holbrook et al 2009 (13)</td>
<td>Pragmatic randomised trial of a complex intervention</td>
<td>To evaluate whether a computerised decision support, shared between patient and primary provider, could improve the quality of diabetes management in primary care</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>Ontario, Canada</td>
</tr>
<tr>
<td>Pedersen 2009 (26)</td>
<td>Observation and cross-sectional study, including a review of medical records and databases</td>
<td>To analyse the management of T2DM in Greenland in 2008</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>No</td>
<td>Greenland</td>
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<tr>
<td>McRae et al 2008 (29)</td>
<td>Effectiveness analysis of programme designed to integrate diabetes care</td>
<td>To address the cost effectiveness of a programme designed to integrate diabetes care and to improve guideline implementation in an Australian Division of General Practice (ADGP)</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>No</td>
<td>Australia</td>
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<tr>
<td>Taggart et al 2008 (18)</td>
<td>Observational; compared patients from two dissimilar divisions of general practice in Sydney’s southwest</td>
<td>To examine trends in the quality of care and intermediate outcomes (biological indicators) for patients between 1995 and 2004</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>No</td>
<td>Australia</td>
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<tr>
<td>Kirsh et al 2007 (27)</td>
<td>Quasi-experimental with concurrent but non-randomised controls</td>
<td>To improve clinic efficiency, a system of redesign based on chronic care model is the Shared Medical Appointment (SMA) (also known as cluster visit), in which groups (8–20) are seen by a multidisciplinary team for a half-hour appointment</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>USA</td>
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<tr>
<td>Jennings et al 2006 (24)</td>
<td>RCT</td>
<td>To test if process and intermediate outcomes for patients with T2 changed with the move to structured care in general practice shared with secondary care</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>Republic of Ireland</td>
</tr>
<tr>
<td>Author/year</td>
<td>Type of intervention study/methods used</td>
<td>Study aims</td>
<td>Processes of care and clinical outcomes measured</td>
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<td>Type of diabetes of patients studied (if applicable)</td>
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<td>Smith &lt;i&gt;et al&lt;/i&gt; 2004&lt;sup&gt;(14)&lt;/sup&gt;</td>
<td>RCT</td>
<td>To assess the feasibility and effectiveness of a structured diabetes shared care service and to analyse the impact on total patient care</td>
<td>Yes (included psychosocial outcomes)</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>Republic of Ireland</td>
</tr>
<tr>
<td>Renders &lt;i&gt;et al&lt;/i&gt; 2003&lt;sup&gt;(22)&lt;/sup&gt;</td>
<td>Retrospective comparison of data derived from two non-randomised trials</td>
<td>Comparing two intervention programmes, aimed at improving the quality of care provided for patients with T2DM in the longer term</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>The Netherlands</td>
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<tr>
<td>Wigertz and Westerling 2001&lt;sup&gt;(28)&lt;/sup&gt;</td>
<td>Cross-sectional</td>
<td>To analyse the usefulness of different healthcare utilisation registers for measures of prevalence of five chronic diseases, with the purpose of finding as many cases as possible</td>
<td>No</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>No</td>
<td>Sweden</td>
</tr>
<tr>
<td>Carinci &lt;i&gt;et al&lt;/i&gt; 2006&lt;sup&gt;(19)&lt;/sup&gt;</td>
<td>Multi disciplinary approaches; created register in the Umbria region of Italy; result of regional and register data linkage is the Reference Diabetes Database (RDD)</td>
<td>To generalise the use of a diabetes register to allow an active use of health information</td>
<td>No</td>
<td>No</td>
<td>Not said/not distinguished/not applicable</td>
<td>No</td>
<td>Umbria region, Italy</td>
</tr>
<tr>
<td>Study Authors</td>
<td>Study Design</td>
<td>Study Aim</td>
<td>Impact/Change</td>
<td>Type of Diabetes</td>
<td>Location</td>
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<tr>
<td>Joshy and Simmons 2006 (10)</td>
<td>Systematic review</td>
<td>To review the provisions for diabetes surveillance in different parts of the world; review of international and national information systems for diabetes surveillance. Included: multiple source registers, excluded: single source databases and experimental intervention trials</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Civil et al 2009 (25)</td>
<td>Pre–post intervention audit and pre- and post-surveys</td>
<td>Pilot study, intervention regarding data cleaning: improve systems of management of electronic registers of people with diabetes in the general practice setting Facilitate an accurate diabetes register through data cleansing</td>
<td>No</td>
<td>Yes</td>
<td>Australia</td>
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<tr>
<td>Eccles et al 2007 (12)</td>
<td>RCT</td>
<td>To evaluate the effectiveness and efficiency of an area-wide extended computerised diabetes register incorporating a full structured recall and management system, actively involving patients and including individualised patient management prompts to PC clinicians based on locally adapted evidence-based guidelines</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td></td>
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<tr>
<td>O’Connor et al 2005 (23)</td>
<td>Longitudinal and controlled study</td>
<td>To evaluate the impact of electronic medical record (EMR) implementation on quality of diabetes care</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes USA</td>
<td></td>
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<td>Author/year</td>
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<td>Location stated</td>
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<td>Renders et al 2000&lt;sup&gt;(8)&lt;/sup&gt;</td>
<td>Systematic review</td>
<td>To assess the effects of different interventions, on the management of patients with diabetes in primary care, outpatient and community settings – targeted at health professionals or the structure in which they deliver care</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>No restriction on location (COCHRANE)</td>
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<tr>
<td>Peterson et al 2008&lt;sup&gt;(11)&lt;/sup&gt;</td>
<td>Clinical trial; group randomised controlled clinical trial evaluating the practical effectiveness of a multi-component intervention</td>
<td>To determine whether implementation of a multi-component organisational intervention can produce significant change in diabetes care and outcomes in community primary care practices</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>Yes</td>
<td>USA</td>
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<tr>
<td>Pollard et al 2009&lt;sup&gt;(16)&lt;/sup&gt;</td>
<td>Pre- and post-design</td>
<td>To examine various levels of use of an electronic registry in contexts where other planned interventions did not simultaneously occur with the onset of the registry</td>
<td>Yes</td>
<td>Yes</td>
<td>Not said/not distinguished/not applicable</td>
<td>Yes</td>
<td>USA</td>
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<tr>
<td>Shojania et al 2006&lt;sup&gt;(6)&lt;/sup&gt;</td>
<td>Meta-analysis</td>
<td>To assess the impact on glycaemic control of 11 distinct strategies for quality improvement in adults with type 2 diabetes</td>
<td>Yes</td>
<td>Yes</td>
<td>Type 2</td>
<td>n/a</td>
<td></td>
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</table>

<sup>a</sup> This column refers to studies that involve the examination of patient groups

<sup>b</sup> This column refers to studies that involve physician groups within the intervention study
outcomes. The COMPETE II study\textsuperscript{13} concluded that the tracking of patients as enabled by the register and associated decision support system (DSS) improved point-of-care monitoring and communication between primary and secondary care physicians but without statistical improvement in clinical outcomes. The North Dublin RCT of structured diabetes shared care resulted in changes in psychosocial measures but no significant improvement in outcomes; although the authors stated that the improvement in shared care arrangements was an enabler for long-term monitoring of patients and incremental improvement of care and outcomes.\textsuperscript{14} The TRANSLATE trial\textsuperscript{11} demonstrated significantly greater improvements in all process measures in the intervention group compared to the control group. There was a significant decrease in the mean A1C value among the intervention group. However both groups showed improvements in other clinical outcomes (mean systolic blood pressure, mean LDL cholesterol). Using a composite score of outcomes the intervention group had significantly greater net improvements in the number of clinical targets achieved for systolic blood pressure, HbA1c and LDL cholesterol compared to the control group. Unlike the studies reviewed previously,\textsuperscript{21} the DREAM trial\textsuperscript{12} found no significant differences in HbA1c levels.

A study investigating the impact of a quality improvement intervention evaluated retrospective data from two non-randomised trials with a 3.5-year follow-up.\textsuperscript{22} The register was a feature within both interventions but was not the core element in either. This study found that a diabetes service which provided general practitioner (GP) training and clinical advice resulted in better glycaemic control than an intervention that sought to improve GP skills alongside organisational changes in general practice.

Another study (using a longitudinal and control design) sought to evaluate the implementation of an EMR system and its impact on the quality of diabetes care. EMR utilisation resulted in an increased number of HbA1c and LDL cholesterol tests being conducted but did not improve metabolic control.\textsuperscript{23}

A ‘before and after’ study examined the impact of the change to structured care using an audit of process and intermediate (biological) outcomes for patients with type 2 diabetes.\textsuperscript{24} Practice patient registers were compiled for the study and used for the baseline audit. The study demonstrated improvements in intermediate outcomes. In terms of patient registration and the use of computerised registers, the study found that the degree of computerisation increased in practices between 2000 and 2004, which had the effect of increasing the use of computers for consultation, problem patient lists and disease registers.

Another study assessed whether diabetes register usage would increase following an intervention to improve data cleaning within the general practice setting. Once the register was updated during or after the intervention by general practice staff, participating practices agreed that a fully functioning and updated register improves management of diabetes care.\textsuperscript{25}

A study conducted in the USA solely investigated the impact of the utilisation of a diabetes register.\textsuperscript{16} It examined not only the use of a diabetes register in the primary care setting, but also the extent of utilisation (use categorised as low, medium or high). The authors found that the use of an electronic register improves process and outcome measures in patients only where utilisation reaches medium to high level. Therefore, it is not sufficient to have a register; it is necessary to use it to a certain degree so as to impact significantly on care and outcomes.

An observational and cross-sectional study included a review of medical records and databases, with the aim of analysing the management of patients with type 2 diabetes in Greenland. Quality of management was based on process and biological indicators. There was great variation in the management of diabetes across the 12 healthcare centres. The study recommended that local diabetes registers need to be established, as patient registration is integral for the implementation of national healthcare policy.\textsuperscript{26}

A quasi-experimental study was conducted with concurrent but non-randomised controls, involving a retrospective period of observation of participants prior to their participation in a shared medical appointments (SMA) system.\textsuperscript{27} A diabetes register was established so that patients could be identified and monitored effectively. The register was a feature of the intervention, to the extent that it was used to facilitate the implementation and evaluation of SMA. The register was used to analyse the process and outcome measures. Significant decreases in the average HbA1c were found in patients involved in the SMA system. Other elements of the intervention included patient education and increased self-management, as well strong emphasis on the provider team approach. This re-emphasises the multifaceted nature of interventions employing a patient register.

The applicability of different healthcare registers for the estimation of disease prevalence was examined for chronic disease in Sweden. This cross-sectional study concluded that a single national register, whereby diagnostic data from both primary care and outpatient care settings would inform the register, would aid the planning and evaluating of services. Data for analysis was extracted from computerised administrative systems which are available locally. The authors concluded that there is a need for a central register, to enable diagnostic information from primary care and from within hospital settings to be brought together.\textsuperscript{28}

An assessment was carried out on the cost-effectiveness of a programme designed to integrate diabetes care in order to improve guideline implementation.
The results were presented in a two-fold manner, namely as improvements in health outcomes and hospitals costs. Results indicated that programmes using a central computer-based register led to greater efficiency of resources by reducing fragmentation and duplication of services.

Discussion

The role of a diabetes register

Although evidence of the effectiveness of specific components of a diabetes care intervention is inconclusive, it is widely accepted that a diabetes register is an essential component of any such programme. Shojania et al acknowledge that patient registration is just one of a variety of quality improvement strategies, but in itself is necessary for framing a high-quality diabetes management system.

In general there is consensus on the fundamental elements that would comprise a comprehensive diabetes service. These elements include (as basic necessities) patient registration, recall and regular review. These three key components have also been identified in an Irish national policy steering document, compiled by the Expert Advisory Group (EAG) of the Health Services Executive (HSE), as necessary in advancing the quality improvement agenda. It may be the case that registration facilitates the other components of an effective system, as demonstrated in a number of studies included here. Diabetes registration systems can be effective in organising patient education and communication, for patients to receive online information and for generating reminders.

Impact on processes of care and clinical outcomes

Diabetes registers and EMRs used for tracking diabetes patients are implicitly and explicitly promoted as effective and necessary management tools with the potential for improving diabetes care. The extent to which this information system is developed, updated and integrated by health professionals into the process of care for diabetes patients depends on whether they believe that a diabetes register will impact on patient quality of care and outcomes.

Modern healthcare systems support the increased use of diabetes registration systems in order to improve the management of patient records and the quality and cost-effectiveness of patient care. Research has demonstrated the disadvantages of paper-based medical systems. The need for computerisation of practices, and furthermore the requirement of centralised computer systems (between practices and between systems of care), has attained a consensus in the literature and throughout good medical practice.

While research shows that computerised decision support systems can change provider behaviour, as yet there have been too few randomised trials to suggest that they improve patient outcomes. This review found that clinical outcomes were modestly improved in most multidimensional quality improvement interventions which utilised and included a diabetes registration system.

Although O’Connor et al question what they call ‘the tenuous link between process and outcome of diabetes care’, the organised care of patients, aided by prompted recall and reminder systems included in standard electronic registers, are necessary ingredients in providing a holistic approach to diabetes management in primary care. Conclusions from the RCTs included in this study, as in all interventions in this review, overwhelmingly illustrate the need for diabetes registers in the management of diabetes patients to enable better organisation of care.

Conclusion

The overarching finding from this review is that a register system is assumed to be the central and underlying feature of a diabetes management programme, without the need for qualification of its existence.

The register is a feature of most quality improvement initiatives. The literature does not argue for or against the need for a register per se, although it does support the concept of a register in enabling structured care and improving patient outcomes. For the most part, the establishment of a register is taken implicitly as an enabler in diabetes management.

Modest results for improved clinical outcomes in patients were found but there were significant positive improvements in the processes of care. This is an integral step along the path towards improved patient clinical outcomes, notably HbA1c, blood pressure and cholesterol measurements. Reasons for the lack of improvement could be the short time span of the interventions, as was suggested by a number of the RCTs.

Pollard et al conclude that the gap between recommended care and the diabetes care that patients receive is significantly wider than for other chronic diseases. In order to bridge this gap, diabetes management programmes and structured care for diabetes,
enabled by a diabetes register, can prove successful in improving patient outcomes.

Research on diabetes registration systems for patients as a separate intervention is limited. It is important to compare effective components in order to move forward from the continued focus on overall effectiveness.

It is widely acknowledged that without adequate clinical evidence, as can be facilitated by a diabetes register system, care may not improve. That is to say, a diabetes register is taken for granted in programmes that seek to improve the quality of diabetes care management. The development of a national diabetes register in Ireland ought to improve both process of care and outcomes of care in diabetes mellitus. A register should provide the infrastructural scaffolding essential for the development of further quality improvement strategies for advancing diabetes care in Ireland.

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REFERENCES
22 Renders CM, Valk GD, de Sonnaville JJJ et al. Quality of care for patients with Type 2 diabetes mellitus: a long-


27 Kirsh S, Watts S, Pascuzzi K et al. Shared medical appointments based on the chronic care model: a quality improvement project to address the challenges of patients with diabetes with high cardiovascular risk. *Quality and Safety in Health Care* 2007;16:349–53.


**CONFLICTS OF INTEREST**

None.

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