Improving Health Outcomes
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Alastair McColl, Paul Roderick, John Gabbay
The diabetes register in Liverpool

Geographical Area covered: Liverpool
Focus: Case studies focusing on the use of national indicators

Contributors:
Authors: Sharon Abdul, Neighbourhood Health Development Worker (seconded to Liverpool Public Health Department to provide an independent overview of the project)
Diana Forrest, Consultant in Public Health Medicine
Address for correspondence: Liverpool Health Authority, Hamilton House, 24 Pall Mall, Liverpool, 3L 6AL

Editorial comments on how case study is linked to improving health outcomes: (also published in Volume 1)

Abdul and Forrest describe the setting up of a primary care based diabetes register in Liverpool (based on a system used in Salford). An objective was to improve the effective management of diabetes to reduce morbidity and mortality. A register was necessary to monitor the use of shared care guidelines, and to obtain local process and outcome measures which were not available from routine data. Secondary coding of diabetes on routine HES data was poor.

Abstract (also published in Volume 1)

Background: An initial audit in primary care of diabetes management indicated the need for improvements in care. Diabetes guidelines were developed, and it was decided to link the implementation of these guidelines with the establishment of a primary care based diabetes register.

Aim: To establish a primary care based diabetes register in Liverpool that will assist in the monitoring and facilitation of diabetes care in both primary and secondary care settings.

Objectives:

To ensure that all patients with diabetes receive regular and appropriate screening for complications.

To facilitate the audit of diabetes care.

To provide data for the planning of diabetes services.

To improve the effective management of diabetes to reduce morbidity and mortality within Liverpool.

Implementation Plan: The register was piloted in 20 practices during 1994. A diabetes facilitator (a nurse with diabetes training) has been employed since March 1995 to motivate primary care staff to collect an appropriate dataset to feed into the register, to analyse the data, and to communicate the results back to the primary care teams.

Of 104 practices in Liverpool, 94 (90%) have so far agreed to participate. Baseline data have been received from all participating practices and stored on the register. Anonymised data have been fed back to primary care team members. A data coordinator has recently been employed to assist in the extrapolation of data, and to develop direct computer links with hospital trust registers, the pathology laboratories and primary care computer systems.

Introduction:
Why this clinical area was chosen:

Liverpool Health Authority covers a population of approximately 474,000. Liverpool is faced with a declining population (Liverpool’s loss of population 1971–81 was the heaviest of any major urban area), an aging population, (with a growth of 25 percent in the number of elderly aged 85+ between 1981-91) and one of the highest hospital admission rates in the country. Like many urban areas, many of Liverpool’s population are faced with high unemployment levels, (22%) and within some wards nearly one in two of the workforce (45%) are unemployed. There are marked variations in SMRs between the wards and deaths from specific causes of death follow the overall pattern of inequality.

In 1992/3 a diabetes audit was undertaken by the Medical Audit Advisory Group (now known as Primary Care Audit Group) within sixteen general practices in Liverpool (all self selecting). The audit illustrated that diabetes care in Liverpool was in need of improvement and it was recognised that effective management of diabetes would reduce both morbidity and mortality. The need for shared care guidelines, and, hand in hand with this, the need for a diabetes register, was apparent. As a result, a guidelines working group, consisting of representatives from the Primary Care Audit Group (PCAG), public health consultants, consultant physicians and GP’s, was set up. One of the members of this group, a diabetes consultant physician, was a product champion for improving diabetes services, and provided the drive to improve diabetes care within Liverpool.

The targets set in the St Vincent’s Declaration (Hussey 1995; WHO 1990) exposed the need to obtain baseline data on diabetes which was not readily available from routinely collected data. Discussions with consultant physicians indicated that they suspected a high morbidity rate from associated renal disease, blindness, and lower limb amputations. However, analysis of hospital statistics showed that the coding of diabetes as a secondary diagnosis was incomplete. A diabetes register was seen as a means of obtaining more accurate data.

The use of diabetes registers has been encouraged as a tool for improved diabetes care both nationally (DOH 1995a; BDA 1993, CSAG 1994) and regionally (North West Regional Diabetes Development Group, 1996). Initial discussions with primary care staff indicated that inequalities in service delivery for diabetes care existed. Some GP’s were more knowledgeable about diabetes, which resulted in variations between practices in the quality of care provided. The diabetes register would highlight this and indicate the level of care that was actually being provided.

Further information that was required:

The Salford diabetes register system was utilised, because this was thought to be the best available system which collected all the necessary data, and was primary care based. It had been tried and tested for a number of years in Salford, and there was a users’ group which met periodically to share any problems or ideas for improvement.

Consultant physicians, amongst others within Liverpool, have been pushing for the implementation of a primary care based diabetes register for a number of years. A register (based on the Salford system) had already been set up within The Royal Liverpool University Hospital (NHS) Trust and it is envisaged that in the future there will be a linkup between the primary and secondary care registers, thereby facilitating communication between primary and secondary care. Wirral, St. Helens and Knowsley and South Sefton Health Authorities are also planning to utilise the Salford register. It is hoped that in the future it will be possible to share intradistrict comparisons regarding the standards of treatment and the incidence and prevalence of diabetes.

The register was initially piloted in 20 practices (16 of the practices involved in the initial diabetes audit and four further self selecting practices) These practices were requested to collect stage one data (see below) from the register of all their diabetes patients. Following the pilot, the register was expanded to all practices within Liverpool.

The data was collected in two stages. Firstly, the basic demographic data, then more detailed data on the management and outcomes for each patient. For the first stage, initiated in March 1995, the following information was requested on all diabetic patients treated within the practice:

- age, address, NHS number, date of birth, sex;
- type of diabetes (NIDDM/IDDM);
- diabetes therapy;
- type of follow-up - GP only/shared care/hospital clinic only.

The second stage is now underway and involves collecting more detailed clinical data about patients seen at annual review. This includes information on HbA1c levels (an indicator of diabetic control), treatment given, referrals made, whether the patient saw a dietitian, and a chiropodist, whether eye screening was done, and the complications of diabetes which were found, for example heart disease, eye disease and renal disease (categorised as yes or no variables). Visual acuity will also be recorded and links will be made with the data collected by the mobile eye screening service.

This information will allow for the collation of short-term, intermediate and long term outcome data at practice, neighbourhood and district levels, with measures including:

- incidence and prevalence of renal disease amongst diabetics;
- incidence and prevalence of foot ulceration and limb amputations;
- incidence and prevalence of heart disease amongst diabetic patients;
- outcomes of pregnancy amongst diabetic women.

Many targets within the St. Vincent’s Declaration have long time scales. Liverpool will therefore monitor process measures so that progress in the short term can also be identified. Such measures will include the quality of annual reviews for diabetic patients (i.e the screening that is being undertaken), the level of ascertainment of patients with diagnosed diabetes (apparent prevalence in practice population as compared to expected prevalence), the proportion of identified patients reviewed within the last year, and the proportion of patients identified as having problems such as foot, eye and renal problems who are receiving appropriate management.

Currently 94 of 104 (90%) practices have agreed to participate. Those practices that are not participating are kept fully informed, and more and more practices are coming on board. It is expected that as a result of peer pressure and accumulation of information, nearly all practices will take part.

**Data validity studies:**

The quality of the data gained varies between practices, with influencing factors including: the extent of computerisation and computer skills within the practice; the quality of information contained within the chronic disease register; and the degree of conscientiousness of the practice staff in checking on the accuracy of the data. All these factors can influence the extent to which the data inputted into the register is valid. Support is provided to practices in an attempt to improve the quality of information obtained. Practices will get feedback, comparing their data with that of other practices; the experience of the Salford project is that such an exercise encourages practices to improve the quality of the data they provide.

**Summary findings from initial work:**

**Changes which were made:**

Initial proposals for the Diabetes Register, based on discussions within the Diabetes Register Working Group, and District Diabetes Working group concluded:

“The Diabetes register should be set up under the auspices of the MAAG, who would receive professional support and advice from the Diabetes Working Group” and that “The Register should be located within the MAAG office”.
(From recommendations to Liverpool Health Authority regarding the 'Development of a District Diabetes Register', January 1995).

However, due to staffing constraints within the Health Authority, the Medical Audit Advisory Group were unable to employ additional staff to provide data input support to the register. Following discussion, agreement was reached with the Central Operations Group (COG - a body independent of Liverpool Health Authority, contracted to provide administrative and operational support to the Health Authority) to house the district diabetes register hardware and manage the processing of the
Debate took place over the need to ensure appropriate use of the register data. It was agreed that the data on the register would be held by the Medical Audit Advisory Group confidential to them and would not be released to Health Authority management, although aggregated data would be available to the Public Health Directorate for strategic planning purposes.

A formal agreement outlining the agreed management arrangements and confidentiality clauses has been drawn up and agreed by the MAAG, COG and Public Health Directorate. Individual contracts between the MAAG and practices participating in the register are offered to all practices.

The register is in its early stages, however, after only eighteen months, a number of changes have been made within primary care as a result of its inception:

- Improved use of data: the data assists practices in reaching a number of data requirements specified by the Health Authority, including data required within annual reports/business plans and for chronic disease management payments;
- Improved communication with secondary care: due to the multi agency steering group, primary and secondary care can openly and freely discuss issues of practicalities of implementation, and provide insight on pressures and demands facing both primary and secondary care;
- Closer working relationships between Departments within Liverpool Health Authority: MAAG, Public Health and COG;
- More people (especially within primary care) are looking at diabetes and thinking of structuring their care of diabetes, and looking at the process measures which will have an inevitable effect on outcomes;
- A data coordinator has recently been employed. There are plans to link the secondary care diabetes registers with the primary care diabetes register. The secondary care registers are linked into the hospital information system, so eventually all systems will be linked.

**How changes will be monitored:**

The progress of the Register is monitored by the Diabetes Register Steering Group, which has quarterly meetings which review: the percentage of practices on the Register; a summary of the information gleaned so far; and progress against the plans. Having received data from 90% of the practices, we now have 6000 patients on the register. However, the estimated prevalence (based on the Salford prevalence) is around 9000, therefore we do not appear to have a complete data set. This matter is being discussed with GPs. It is possible that the main omission is of diabetic patients who are treated with diet only. It will take at least another year before the register will be able to provide useful outcomes data on diabetes, which can be used as a baseline against which to monitor improvements.

**Resource Implication:**

Since April 1995, the Health Authority has allocated £30,000 per year towards the diabetes register. This covers the capital costs of the register, the costs of the diabetes facilitator (half time) the data administrator (half time) and the part time data input clerk. This amount has proved sufficient in the first year, but as the register progresses, the figure will be reviewed annually.

The implementation of the register has used the time of all those on the Register Steering Group, including the PCAG Coordinator, the Consultant Physician, the Public Health Consultant and the GPs. Each practice involved in providing data for the register has had to use a number of hours of practice staff time.

**Practical lessons learnt:**

A number of issues have assisted in the progress of the register. The implementation of the Liverpool diabetes shared care guidelines (launched at the same time as the diabetes register) has put ‘diabetes’ and the need for structured diabetic care high on the primary care agenda, and consequently, many practices have willingly participated in bringing about change on a population basis. The Primary Care Audit Group has had a very important role in this, including that of advocate,
mediator, events organiser, encourager, all of which have assisted in smoother implementation of the register than may otherwise have been.

An awareness of the increasing pressures on primary care staff has resulted in support being provided from the outset to the practice nurses providing information for the register. If this practical support had not been available, many feel that the implementation process would have been hampered. This factor, coupled with the dogged determination of key individuals (who believe in the register and have kept promoting it) highlight the prerequisite components for any successful project: ‘support and determination’.

The initial piloting of the project within twenty practices in Liverpool, has also allowed for any practical problems to be quickly dealt with. Effective communication with other Health Authorities who have previously established diabetes registers, has made for a more effective, more knowledgeable and more speedy implementation of the register within primary care.

The establishment of the register has, like many projects, not been without its complications. A few GPs are still suspicious of the use of the data, and are concerned that information on the register could be used against them as a health authority ‘weapon’. Despite many assurances it is evident that only time will allay these fears. Initial teething problems have resulted in lost time; the support and training for the register provided by Salford has been limited, (although invaluable) therefore necessitating the employment of a data administrator. Although practical support has been provided, GPs regularly reiterate the increasing demands that accompany a ‘primary care led NHS’. The diabetes register is ‘scoring high’ on the GPs’ and practice staff priority list, however, in practice, they, like many health service workers, have competing demands on their time. The needs of patients and of other projects have resulted in late returns of datasets from some practices, and a resultant slip in the timescales of the register.

**Conclusion:**

The Diabetes Register is now up and running within Liverpool, and 90% of practices have provided baseline information. A large number of people are involved at various levels, including practice nurses, non medical staff, GP’s and consultants, all of whom have a valuable role to play in shaping future diabetes care services. The implementation of the Register is a long term process that requires continued commitment and support. The process itself keeps diabetes care high on the agenda, and the register promises to be a useful tool for improving diabetes care.

**References:**


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Organisational Context:

'Population health outcomes assessment’, 'health impact' and 'health gain' are terms commonplace within Liverpool Health Authority departments, such as public health and primary care. Increasingly, Health Authority staff, such as public health consultants and neighbourhood commissioning managers, utilise health outcome indicators, (including a small number of indicators cited by the Department of Health), when assessing health care interventions. As such, investments are being targeted at those areas of recognised benefit, especially around areas of evidence-based health care.

With the adoption of the City Health Plan, there is a realisation that collective action is required by statutory, voluntary and community sectors if we are to make Liverpool a truly ‘Healthy City’. Terms, including 'health gain’ and health outcomes are increasingly being used within these sectors, and people are now more focused on how they can maximise health in the city. Only by utilising population health outcome indicators, will the sectors ascertain the extent to which they have achieved this goal by the year 2000.