This case study describes how a strategic review for diabetes identified models of service provision and desired health outcomes for use as measures of progress towards agreed targets for health gain. Eight key service target areas were developed which were linked to improved health outcome and for which process measures could be developed and monitored.

Abstract (also published in Volume 1)

Diabetes was chosen as a topic because it is a common local cause of morbidity and mortality. Good health care can result in substantial health gain. There was local evidence that services were poorly co-ordinated and that important programmes such as retinal screening did not reach all diabetic patients. A strategic review group for diabetes was set up by East Kent Health Authority and reviewed the local information on the prevalence of diabetes and its complications. A literature review identified desired health outcomes and models of service provision. Local services were reviewed and as a result health outcome assessments were identified for use as measures of progress towards agreed targets for health gain. Specific targets used were the number of amputations and the number of cases of end stage renal failure among the diabetic population. Local prevalence information derived from General Practitioner Annual Reports was found to be more useful than nationally derived predictions. Detailed service specifications were drawn up and funding allocated for specific service developments. The priority proposals included the setting up of community based diabetic teams, the development of shared care guidelines, provision of patient information, clinical audit and the designation of a lead clinician in each Trust. The priority proposals included the setting up of community based diabetic teams, the development of shared care guidelines, provision of patient information, clinical audit and the designation of a lead clinician in each Trust. Health outcome measures will be used to monitor changes resulting from service development.

Introduction:

Why this clinical area was choosen:

Diabetes was chosen as a topic for strategic review because it is a common cause of morbidity and mortality. The age adjusted prevalence of clinically diagnosed diabetes (all types) in England is commonly quoted as being between 1.05% to 1.36% (Williams 1994). However, this is thought to be an underestimate of the true prevalence. It is a chronic condition with a range of complications, and regular screening requires co-ordination of services between specialists and General Practitioners. The organisation of care for individuals with diabetes mellitus, both insulin dependent diabetes mellitus (IDDM) and the most common type, non-insulin dependent diabetes mellitus (NIDDM), is an example where good health care can result in substantial health gain. However this will not occur spontaneously and focused management is required to achieve this potential.

A voluntary organisation had begun to offer a mobile retinopathy screening service to some local GPs. This highlighted gaps in provision and wide variation between GPs in the management of diabetes. In particular,
there was concern about the limited coverage of the retinopathy screening and limited access to day centres for some residents. Health outcome indicators were presented to the strategy review group and highlighted these variations and influenced the choice of this clinical area for further study.

Further information that was required:

A strategic review programme was set up to review local information and to review the relevant literature.

A) Local information

Estimation of prevalence of diabetes

An estimate of the prevalence of diabetes is necessary for the denominator of health outcome assessments. The two population characteristics which most strongly influence the numbers of people with diabetes are:

- The age and sex structure of the population;
- The ethnic mix of the population, particularly the proportion of residents of Asian and Afro-Caribbean origin.

The prevalence of diabetes was estimated using prevalence studies from national studies and from local GP data. In calculating the estimated numbers of people in East Kent with diabetes, prevalence figures estimated by Williams (1994) in his report on national epidemiological studies were used in addition to estimates using a second independent set of figures derived from the Annual Reports of local General Practitioners. These two methods yielded widely differing results (table 1).

<table>
<thead>
<tr>
<th>Age Band - years</th>
<th>1995 Projected population</th>
<th>Williams’ estimate</th>
<th>East Kent GP estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-9</td>
<td>71990</td>
<td>39</td>
<td>67</td>
</tr>
<tr>
<td>10-19</td>
<td>70270</td>
<td>137</td>
<td>236</td>
</tr>
<tr>
<td>20-29</td>
<td>74180</td>
<td>304</td>
<td>522</td>
</tr>
<tr>
<td>30-39</td>
<td>75570</td>
<td>354</td>
<td>609</td>
</tr>
<tr>
<td>40-49</td>
<td>79540</td>
<td>596</td>
<td>1025</td>
</tr>
<tr>
<td>50-59</td>
<td>65270</td>
<td>897</td>
<td>1543</td>
</tr>
<tr>
<td>60-69</td>
<td>60310</td>
<td>1252</td>
<td>2148</td>
</tr>
<tr>
<td>70-79</td>
<td>55150</td>
<td>1970</td>
<td>3390</td>
</tr>
<tr>
<td>80+</td>
<td>33890</td>
<td>1065</td>
<td>1832</td>
</tr>
<tr>
<td>Total</td>
<td>586170</td>
<td>6614</td>
<td>11364</td>
</tr>
</tbody>
</table>

All GPs were asked to report the total number of diabetic patients in their practice. Those who replied gave a single prevalence figure not broken down by sex or age group. No check on accuracy was possible and these estimates should be used with caution.

The actual numbers of people with clinically diagnosed diabetes in a locality will be partly dependent on the extent by which screening and case finding activities have revealed the presence of undiagnosed disease, specifically NIDDM. In East Kent there are few people of Asian or Afro-Caribbean origin, nevertheless it is expected that greater numbers than the nationally expected rate of approximately 1.1% would be identified through increased case finding.

Complications of diabetes

The main complications of diabetes are eye diseases, retinopathy and cataract, neuropathy, renal disease, peripheral vascular disease and cardiovascular disease. We were unable to obtain local prevalence figures from routine data sources for complications of diabetes. The prevalence and expected number of common complications are shown in tables 2, 3 and 4.

<table>
<thead>
<tr>
<th>Level of visual acuity (DVA= Distant visual acuity)</th>
<th>Prevalence per 1000 diabetic population</th>
<th>Estimated number 1995</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Good” (DVA 6/7 or better)</td>
<td>870</td>
<td>5754</td>
</tr>
<tr>
<td>“Impaired” (DVA 6/12 to 6/60)</td>
<td>110</td>
<td>726</td>
</tr>
</tbody>
</table>
Table 3: The percentage and estimated number of diabetic neuropathy and foot ulcers in East Kent for the year 1995.

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Neuropathy (%)</th>
<th>Estimated numbers</th>
<th>Foot ulcers (%)</th>
<th>Estimated numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-59</td>
<td>17</td>
<td>366</td>
<td>2</td>
<td>43</td>
</tr>
<tr>
<td>60-69</td>
<td>42</td>
<td>526</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>70+</td>
<td>10</td>
<td>304</td>
<td>8</td>
<td>242</td>
</tr>
</tbody>
</table>

Source: Williams, R.

Table 4: The prevalence and estimated number of all diabetics with hypertension, possible myocardial infarction, angina, intermittent claudication, stroke and lower limb amputations for East Kent residents, 1995.

<table>
<thead>
<tr>
<th>Age</th>
<th>Hypertension</th>
<th>Myocardial infarction</th>
<th>Angina</th>
<th>Intermittent claudication</th>
<th>Stroke</th>
<th>Amputations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prevalence (%)</td>
<td>No</td>
<td>Prevalence (%)</td>
<td>No</td>
<td>Prevalence (%)</td>
<td>No</td>
</tr>
<tr>
<td>20-59</td>
<td>24</td>
<td>516</td>
<td>3</td>
<td>65</td>
<td>5</td>
<td>108</td>
</tr>
<tr>
<td>60-69</td>
<td>46</td>
<td>576</td>
<td>4</td>
<td>50</td>
<td>12</td>
<td>190</td>
</tr>
<tr>
<td>70+</td>
<td>56</td>
<td>1700</td>
<td>11</td>
<td>334</td>
<td>11</td>
<td>335</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>2792</td>
<td>7</td>
<td>449</td>
<td>9</td>
<td>592</td>
</tr>
</tbody>
</table>

Source: Williams, R.

Local data on the complications of diabetes

Attempts were made to set health gain targets derived from the St Vincent Declaration, namely:

- To reduce new blindness by a third.
- To reduce by half the rate of limb amputations for diabetic gangrene;
- To achieve a pregnancy outcome in diabetic women that approximates to that of non-diabetic women;
- To reduce the numbers of people entering end stage renal failure by a third;
- To cut morbidity and mortality from coronary heart disease in people with diabetes by programmes of risk factor education.

Of these only limb disease and renal failure proved possible to analyse in a meaningful way.

All hospital Patient Information System records were searched and any in-patient or day-case episode with a diagnostic code for diabetes were identified and examined in order to establish whether a patient was recorded as being diabetic and had an amputation or end-stage renal failure. Three year rolling averages were calculated for the years 1988 to 1994 for lower limb amputations and for end stage renal failure. These are shown in figures 1 and 2.

For lower limb amputations, approximately 40 are performed amongst diabetics each year. Thus to cut this figure by 50% by the year 200 requires a reduction to 20 amputations a year. For end stage renal failure approximately 34 cases occur among diabetics each year, and the required reduction would be from 34 cases to 22. It should be noted that changes in data quality may require these targets to be adjusted in the future.

Figure 1: Lower limb amputations for East Kent diabetics 1990-1994 3-year rolling averages and target for year 2000.

Note: Amputations classified by OPCS codes X09, X10 and X11; amputations of leg, foot and toe respectively. A patient is classified as being diabetic if ICD code 250 appears in any of the seven diagnostic fields of the hospital records.
Figure 2: End stage renal failure among East Kent diabetics 1990-1994 3-year rolling averages and target for year 2000.

Years
Note: End stage renal failure defined by ICD codes A585 and A586; chronic renal failure, and renal failure (unspecified) respectively. A patient is classified as being diabetic if ICD code 250 appears in any of the seven diagnostic fields of the hospital records.

Due to poor data from the Patient Information System it is not known whether these figures are an accurate reflection of the true incidence and prevalence of diabetic renal disease.

B) Literature review
A literature review including recommendations by the Clinical Standards Advisory Group (1994) identified the main desired health outcomes for people with diabetes. These are described below.

Data validity studies:
The results obtained from the Annual Reports of General Practitioners must be treated with some caution. Reports containing numbers of patients suffering from diabetes only covered 65% of the population and it is not known whether there is any bias through selection of practices which collected the data and reported on it. No independent study of accuracy has been made. It is, however, reassuring that the number of NIDDM reported was greater than expected, suggesting a reasonable coverage (table 5).
There are three relevant population outcome indicators in the Public Health Common Data Set (Department of Health 1995) These are the hospital episode rates for diabetic ketoacidosis, operation rates for lower limb amputations, and mortality from diabetes mellitus in the age group 1-44 years. Figures for lower limb amputation were similar to rates from local data capture.

### Summary findings from initial work:

### Changes which were made:

To obtain desired health outcomes eight key areas were identified, and these are listed below. Most of the specific service targets are process targets which at some point must be related to outcomes. Developing further evidence of this linkage is probably beyond the scope of individual Health Authorities, but should be available from national clinical trials and studies.

1. **All people with diabetes within East Kent should be identified as early as possible into the condition.**

   This should be achieved by screening high risk groups. The Health Authority will work with providers of health education and health promotion to ensure a focused programme of information among high risk groups. General population screening, for example, by issuing self-test kits, may be beneficial but must be subject to rigorous cost-benefit evaluation prior to introduction.

2. **All people with diabetes should receive continuing preventive care from a diabetes team aimed through education and medical interventions at normalising metabolic state according to published targets whilst maintaining quality of life.**

   For the care of the newly diagnosed, purchasers should develop a service specification containing the standards of clinical care prescribed by the Clinical Standards Advisory Group to the UK Health Ministers and to the NHS (Clinical Standards Advisory Group 1994) and negotiate with providers in order to ensure a comprehensive range of services.

3. **All people with diabetes should have immediate and direct access to a diabetic team in both primary and secondary care in order to deal with changes in metabolic state, concerns over diabetes and its management and social difficulties arising from their diabetes.**

   This will require training in the care of diabetics for primary care staff as well as better co-ordination between primary and secondary care.

4. **All people with diabetes should have access to an annual review for complications of diabetes and where a failure of such preventative care is detected, a suitable care plan is agreed to manage the complication and implemented.**

   An annual review should include an assessment of metabolic control, an eye screening service, foot inspection and identification of risk factors for and markers of complications. The attainment of improved outcomes for foot ulceration, renal failure, visual impairment and cardiovascular disease should be aimed for. Responsibility for the annual review should rest with the GP unless formally delegated to the diabetic...
5. People with diabetes have a major role to play not only in their own self-management but also in the development of a service of which they are part.

This can be brought about through communication between professionals and users of the service and through patient representation on the local Diabetes Advisory Group. The Health Authority supports this group which includes members from the British Diabetic Association (BDA) and Community Health Council (CHC).

6. Diabetes teams should be examining on at least an annual basis the success of care being delivered through the aggregation from the results of metabolic outcome measures and true adverse patient outcomes.

The Health Authority, working with providers must agree processes that enable the annual systematic clinical audit of services, using some of the Medical Audit Advisory Group and Hospital Clinical Audit initiatives.

7. People with diabetes should be recorded on a register which should be updated annually to confirm that care is continuing.

Registration is important for future diabetes care programmes as it will establish reliable information baselines, facilitate the co-ordination of services and enable assessment of care. A register is being created by the retinopathy screening programme which is now funded by the Health Authority. This will form the basis of a local register.

8. Diabetes management in special situations.
   a. Pregnancy - Specific services should be made available to pregnant women concerning diabetes. Counselling and advice should also be offered to every woman known to be diabetic of child bearing age who might become pregnant.
   b. Children and young people - Specialist services for young people should follow the BDA guidelines.

The review document was written in a format suitable for development into a disease management contract, and changes to service configuration, data capture and audit are being pursued through the commissioning process. Inclusion of primary care in the specifications is implicit through the working arrangements with secondary care. Primary care can only be fully and explicitly included if disease management contracts are developed.

How changes will be monitored:

The progress of the strategy will be monitored by a standing Diabetes Liaison Group and outcomes will be measured against the internationally agreed targets of the WHO St. Vincent Declaration. Clinical audit topics are agreed with hospital and community Trusts on an annual basis as part of the service contract. Discussions are also held with the local MAAG and specific funding allocated for diabetic audit.

The denominator will be all diagnosed diabetic people in East Kent. Further effort will be made to ensure the accuracy of GP data and to extend its coverage to more practices. This will also be validated through the register which is being created as part of the annual visual screening programme.

The numerator for both amputations and end stage renal failure will continue to be the hospital record system. It is expected that the designation of a lead clinician and the regular audit activity will gradually improve the quality of this data.

Resource Implication:

The development of strategy, monitoring and analysis of outcome measures are an integral part of the commissioning process and are usually undertaken by the Public Health departments of Health Authorities in collaboration with others. The use of health outcome measures in themselves does not generate the need for new resources but may require changes in the use of existing resources. Clinical audit by consultants and GPs is funded by Health Authorities, and diabetes can be audited using existing resources. Service developments do have to be funded by growth funds or by reallocation from elsewhere in the NHS budget. Proposals include appointment of additional specialist staff, for example, clinical nurse advisors, extending existing programmes of care, for example, retinal screening. Other service developments such as a new diabetic day centre can be very expensive and are unlikely to be funded in the short term other than coincidentally as part of larger changes in services or with locally raised and donated funds.
In deciding priorities the Health Authority was influenced towards funding additional nurse advisors on the recommendation of the Advisory Group because they were seen to have a key co-ordinating role, and funding the expansion of retinal screening which has well documented benefits and is evidence based. Funding for a new day centre was rejected on grounds of cost but may be agreed as part of a hospital development scheme.

**Practical lessons learnt:**

As soon as Health Authorities turn their attention more to health gain and the aim of improving the health of the population, as compared with providing health services, the question "What outcome can be achieved?" becomes of central importance. The specification of desired outcomes and the means to their attainment focuses on a new set of issues and identifies a new ordering of priorities. The main lesson to be learnt is how to work in co-operation with clinicians and patients to improve services and management of diabetes to achieve desired outcomes, and to accommodate different goals and perspectives.

Contracting has traditionally been carried out based on facilities rather than disease groups. Changing to a disease base is difficult but has significant advantages if improved service co-ordination for chronic conditions is achieved. The challenge faced with diabetes is to provide effective services to a large number of people in the community with a combination of specialist and primary care services. There is a need for good communications with clarity of roles and responsibilities. Some screening services, for example retinal photography, should be provided to the whole diabetic population in a co-ordinated programme. The involvement of patients in the management of their disease and in shaping the types of service provided is also crucial in any chronic condition; services must be patient-centred to be successful.

Outcome measures give a new insight into priorities from a population-based perspective. Targets can be set for the reduction in the complications of diabetes and monitoring can identify progress towards targets and highlight problems when they arise. One difficulty which must be overcome is that much of the relevant data, including the prevalence of diabetes, is not collected for the purpose of monitoring disease groups. There are difficulties in collecting and validating this data which need continuing attention. The commissioning process will continue to require this data regularly and repeatedly. There is also a need to establish more accuracy in data collected for monitoring purposes.

Information from primary care is particularly difficult to collect. Where it is available, for example in practice annual reports, it is not usually possible to validate its accuracy. This seriously limits its usefulness, however, GPs and others value locally collected data and it is helpful in gaining their participation and support for service changes. Increased use may lead to improved accuracy in the future.

Process measures are more easily collected than outcome measures and can provide a useful indication of good practice, especially if the information can be attributed to individual patients, e.g. hospital admissions for diabetic complications, chiropody visits.

**Conclusion:**

Substantial health gain can be achieved by better co-ordination and universal provision of services for the treatment and monitoring of diabetes. Outcome measures identify the key health gain areas and assist in setting priorities for service development. They also measure progress towards targets for the reduction of morbidity and mortality among the diabetic population. A higher than expected prevalence of diabetes was identified by locally derived data.

Recommendations were made by the Strategic Review Group for each of the key service target areas. The priority proposals included the setting up of community based diabetic teams, the development of shared care guidelines, provision of patient information, clinical audit and the designation of a lead clinician in each Trust.

This case study demonstrated the usefulness of gathering locally generated data. The stark difference between nationally projected incidence and prevalence rates and locally collected data was an important influence in gaining local support for the strategic review process; it demonstrated participation and was seen as more relevant. There was also more confidence in the local figures produced which were accepted, whether rightly or wrongly, as being more accurate. This is likely to increase their use and accuracy in the future.

Further work is required in developing outcome measures and routinely collecting data for their measurement.

**References:**
A) Diabetes in East Kent


Organisational Context:

Population health outcome assessments focus attention on health gain and what action is likely to be effective in achieving health gain. Health outcome assessments are important because they provide the scientific basis with which Health Authorities can justify their policies and ordering of priorities. They provide the argument on which to allocate the funds available for health services; namely, to achieve the greatest health gain possible within the financial constraints. Individual GPs and hospital clinicians may have a different set of priorities and a powerful set of arguments for more resources relating to the best interests of the patients under their care. It is only by structuring the evidence about health gain and allowing health authorities to make prioritising decisions based on relevant information that a proper balance can be found between competing claims to the same resources.

East Kent Health Authority takes a very pro-active view on using health gain and health outcome as a basis for developing strategies and implementing service changes. It has carried out a number of health service reviews across East Kent and uses these to undertake commissioning as a tool to effect changes.