BIRO

An Evidence-Based Diabetes Information System to Support European Health Policy

J. Azzopardi

Cyprus Investigators Meeting

May 2007

Evaluation

Evaluation will assess the effects of BIRO on:

- Improved knowledge of the disease
- Benchmarking and decision making at population level
- Ability to monitor short term health outcomes and track major risk factors
- Quality of life

Work Packages

- Work Package 2 - Clinical Review
  - Institute of Medical Technologies and Health Management: Joanneum Research
    Graz, Austria
- Work Package 3 - Common Dataset
  - Dundee University Clinical Technology Centre, Ninewells Hospital and Medical School
    Dundee, Scotland

Evaluators

- Epidemiology: Amanda Ingham Adler
  - Clinical Lead, Diabetes, Addenbrooke's Hospital, Cambridge University Teaching Hospitals Trust
  - Research Associate, Diabetes Trials Unit, Oxford
  - Honorary Clinical Epidemiologist, Medical Research Council Epidemiology Unit, Cambridge
- Clinical Diabetes expert: Fred Storms
  - Mesos Diabetes Centrum, Bilthoven, Netherlands
  - Project Leader Eucid
  - DiabCare Project

The Reports

- Work carried out according to the technical annex of the contract
- Content covered is appropriate
- Innovative in organisation & effort involved
- Enormously useful to decision makers
  - particularly if data is validated & limitations pointed out
- Stakeholders include governments, insurers, and patient care organisations

Clinical Review – Aims

- Define clinical guidelines and gold standards for diabetes care & prevention
- Basis for construction of models for
  - analysis and routine evaluation of systems of diabetes care in participating regions
- Outputs will directly be used for the production of the data dictionary

Large amount of work in writing the report

Content: Suggestions to add

- Universal screening for diabetes
- Pharmacological and surgical therapies for glycaemic control and obesity
- Broader category for Diabetes in Pregnancy

Scientific Quality

- Report recognises importance of high-quality evidence
  - Bigger priority to be given to well planned meta analyses
    - NICE and Cochrane Collaboration
- All major sources of information, including work done previously, should be cited even if not reviewed
  - data from studies sponsored by Clinical Trials Service Unit, Oxford
  - MRC Clinical Epidemiology Unit
  - experience related to retinopathy (& diabetes screening) from the UK National Screening Committee
  - Others

Scientific Quality

- Quality evidence not always clearly indicated as such
- Some of the sources used are not listed
- Some of the cited references do not support the preceding statements

Report structure

- Needs to be improved for clarity
  - Need for a clear method of cross-referencing
  - Distinguish between data and indicators
  - Different dimensions of validity (for example, face vs content) were defined, but not categorised as such
    - relevance of this distinction was not clear
- Should improve with time

AIM

- A more complete description of the envisioned data set and structure
- Provider-level measures should distinguish between
  - patient-level data
  - summary-measures

Data items

- Obesity
  - WC and BMI
- Risk profile – glucose
  - Why not age?
  - No evidence for fast-acting carbohydrates
- Blood pressure control
  - Spironolactone
- Lipids lowering therapy
  - Gemfibrizol and fish oil supplementation
- Education/Empowerment
  - include relation between health promotion, exercise and weight loss

Data items

- Health Related Quality of Life
  - do complication specific Quality of life measures also exist?
- Acute complications
  - hypoglycaemia and hypoglycaemia requiring medical attention
- Eye complications
  - Cataracts and surgery, Vitrectomy
  - medical, non-laser treatment of retinopathy
    - intraocular ranibizumab and other anti-VEGF agents (bevacizumab)
- Nephropathy
  - distinguish between plasma and urinary creatinine
  - "Nephropathy incipient/manifest" are not clear terms
  - Specify whether GFR is estimated or directly measured

Data items

- Neuropathy:
  - Clinical indicators for PSN need to be more detailed
    - add 10 g monofilament, & specify number and locations to be tested
    - the Seattle Foot Study and the merit of different testing modalities
    - autonomic neuropathy. Add specific measures (e.g. postural BP drop etc)
- CVD
  - "coronary heart disease" rather than "angina" Why not include TIA?
  - The evidence base for type 1 diabetes should include:
    - the work based on cohort from Pittsburgh
    - EDIC (Epidemiology of Diabetes Interventions and Complications) observational post-study monitoring from the DCCT
    - The Haffner reference is insufficient to provide an evidence base for CVD

Data items

- Foot
  - Term “Pharmacologic therapy on foot disease” is vague
  - Include prevalence rather than incidence of amputations
- PVD: more specific definition needed based on
  - pedal pulses and ankle-arm indices
- Population and socio-economic factors
  - Terms like “Rate of urbanisation” & “life-expectancy” need specific definitions & specific numerators & denominators
  - Monica data more relevant to Europe than from New Zealand

Data items

Expenditures

- Do these refer to costs of diabetes care separately
- NICE will have information on the relevant costs
- Costs of lifestyle intervention may be appropriate

- Documentation
  - Consider mortality as one form of monitoring

Data Items

- Health Care resources & delivery
  - Manpower: dieticians, podiatrists, cast technicians & opticians

Expenditures

  - Do these refer to costs of diabetes care separately
  - NICE will have information on the relevant costs
  - Costs of lifestyle intervention may be appropriate
- Documentation
  - Consider mortality as one form of monitoring

Epidemiology: Indicators and definitions

- Standardise the terminology in section headings
  - e.g. percent/prevalence
- Clarify what a "standardised new diagnoses" means
  - Age-standardised? Standardised definition?
- Prevalence of "IGT & diet" not to be lumped together
- IGT diagnosis (OGTT) is not universally performed
  - Consider not providing this statistic
- Annual incidence of ESRD may involve double-counting
  - one may start dialysis & undergo a transplant in same year

Indicators and definitions

- Assign a common denominator for various complications
- Need a stricter definition of no of doctors working in diabetes clinics in 1^{ary} or 2^{ary} care per population
- Assess ratio of patients over or under a defined age
- Some indices are defined by > one concurrent condition
  - this makes them difficult to assess
  - e.g. "% with microalb. or treated for existing nephropathy"
    - How would this be defined?
      - As blockade of angiotensin system, glycaemic control, haemodialysis?

Indicators and definitions

- Retinopathy: How does one define a “trained caregiver”?
- Why is alcohol use sought?
- Diabetes education: Does mean a formal program?
- Thrombolytic therapy
  - Consider number of strokes treated with thrombolysis
- Insulin
  - For combination therapy with OHA’s specify diabetes type
  - Type of insulin therapy
    - list biphasic, prandial, basal, basal bolus, or continuous sc insulin
- Type of blood pressure measurement
  - Is this valid data?

Indicators and definitions

- Why not include:
  - number of classes of glucose lowering drugs
  - proportion of patients on statin therapy
- HbA1c cut-offs are arbitrary
  - consider using the UK Quality and Outcomes Framework (QOF) of the new General Medical Services contract
- Percentage of patients with waist circumference
  - is this routinely collected?
  - possibly better to depend on epidemiological studies
- Is drug abuse data useful?

Common Dataset: Aims

- Define a minimum dataset as a common reference for extraction of compatible entities at international level
- Create a coding/decoding system to translate regional data into a shared information system

The Report

- Work carried out according to the technical annex of the contract
- The relevant literature included
- Current development in Europe is reflected as well as possible
- Report well designed and easy to read
- Some gaps that are reported later

Data Items

- Date of Diagnosis: Year, rather than date
- Cigarettes per day: What about cigars: 1 cigar is also equal to 3 cigarettes?
- Alcohol intake: Glasses per week
- Weight: one decimal is sufficient
- Microalbuminuria: Normal or abnormal

Data Items

- Include LDL cholesterol
- Include active ulcer
- Amputation: Distinguish above from below knee
- OHA: Include option for all categories
- Nasal therapy: Change to inhaled Insulin
- Average injections: Pump is here out of place

Data Items

- Look at EUCID code book for regional databases parameters
  - Does the database for instance covers a complete region or only part of it
  - Is the complete age range included
  - Are all ethnic groups included? Etc
- Diabetes: In EU specialist registers Diabetes and Endocrinology are lumped together

Data Items

- Make a separate indicator: patients treated with insulin only, not combination therapy with tablets. 41 includes the combination therapy
- Also include the guideline goal: percentage of patients with a HbA1c > 7% of < 7%

Data Items

- Add two parameters:
  - Percentage of patients using alcohol
  - Average alcohol use in glasses per day for people who consume alcohol