



B.I.R.O.

Best Information through Regional Outcomes

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WORK PACKAGE 4
D4.1: DATA DICTIONARY

DOCUMENT V0.2

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1. Summary

The purpose of BIRO Work Package 4 is to create an electronic directory inclusive of concept and data dictionaries for diabetes care and prevention, thereby allowing dynamically links to the clinical knowledge-base and to the systematic evaluation of health systems outcomes. This electronic dictionary will tie in closely with the clinical indicators developed in Work Package 2 and the minimum common dataset defined in Work Package 3.

After the creation of the data dictionary, clinical experts have been involved in a qualitative examination of data to ensure that appropriate data mappings and standards have been maintained. This process will define the structure of a relational database that will be available to all partners and which will provide mapping functionality to migrate original datasets to the common structure.

2. References

BIRO WP2 Clinical Review Indicator Development Results

BIRO WP3 Common Dataset

Scottish Diabetes Core Dataset:

<http://www.scotland.gov.uk/Publications/2003/01/16290/17629>

The Australian Diabetes, Obesity and Lifestyle (AusDiab) study:

http://www.diabetes.com.au/AusDiab/AusDiab_2000_data_dictionary.htm

NCDDP (National Clinical Dataset Development Programme):

<http://www.clinicaldatasets.scot.nhs.uk/>

<http://www.datadictionaryadmin.scot.nhs.uk/>

Wikipedia Data Dictionary Definition:

http://en.wikipedia.org/wiki/Data_dictionary

NHS Data Dictionary:

<http://www.datadictionary.nhs.uk/index.asp>

Australian Institute of Health and Welfare Metadata Online Registry:

<http://meteor.aihw.gov.au/content/index.phtml/itemId/276533>

The International System of Units (SI):

<http://www.bipm.org/en/si/>

Scottish Diabetes Core Dataset:

<http://www.scotland.gov.uk/Publications/2003/01/16290/17629>

Scottish Intercollegiate Guidelines Network: SIGN 25

<http://www.sign.ac.uk/>

3. Document Change History

Version	Date	Author	Reason for Update
0.1	May 2007	Scott Cunningham	Initial Template
0.2	July 2007	Scott Cunningham	Revision following Cyprus meeting and further development

4. Data Dictionaries and Data Standards

The development of data dictionaries and data standards can be used to improve the quality, relevance, consistency, availability and comparability of national information about the health. The rationale for the BIRO Data Dictionary arises from the need for better information and automated collection of data on Diabetes Outcomes throughout the European Community.

Data dictionaries can be used to describe the expected meaning and acceptable representation of data for use within a defined context. The need for consistency of meaning and clinical definition is vital to facilitate information sharing among all end-users of the data. Much of the work involved in establishing a data collection methodology is in the development of data standards to ensure comparability and consistency of the data collected and produced from the collection.

This is imperative for the BIRO model as data will be collected across seven European partner sites, all using varying data standards and collection techniques. As BIRO expands to further partner sites, this data dictionary will form the cornerstone for the data collection and analysis. As data is shared then we need to ensure that all of those who need to use the data can clearly understand the meaning regardless of how the data is collected or stored at source.

Metadata

Metadata is often referred to as data about the data. Specifically, it is the definition or structured description of the content, quality, condition or other characteristics of the data. It is well accepted in the world of statistics and database warehousing that metadata leads to better data and subsequent analysis. This is because they enable all people collecting, using and exchanging data to share the same understanding of its meaning and representation.

In BIRO, WP3 described each of the relevant data items for the project, but also some of the metadata associated with it. For example, information on the test name, units of measurement, clinical definition, data type and a flag indicating the comparability of the data. These representation definitions include how data elements are stored in a computer structure. Well-defined, agreed and precise clinical data definitions are essential to ensure that the data is collected in an internationally consistent way.

5. Methodology

BIRO Work Package 2 has created a list of Core Indicator Candidates based on the published scientific literature. Within this the scientific justification for each of the corresponding data items is included.

BIRO Work Package 3: Common Dataset identifies the data items required to fulfil the requirements of the core indicator list. This has been defined on the basis of the compatibility of each parameter across each dataset. Work packages 2 and 3 defined metadata required for the BIRO Data Dictionary (D4.1). Work Package 4 will further enhance this to define the key items and how these will be stored in the central repository. Items defined until now include:

- Clinical Parameter e.g. Height
- BIRO Reference: e.g. BIRO12
- Field Name: e.g. HEIGHT
- Data Type: e.g. Real (nnn.nn)
- Definition: e.g. Height in metres - measured without shoes. It is particularly important to measure regularly the height of children. In adults a single recording will usually be sufficient.
- Units of Measurement: m (metres)
- Lower Range: e.g. 0.4
- Upper Range: e.g. 2.5
- Mandatory (Y/N): e.g. No
- Validity: High/Medium/Low
- Data Mapping: e.g. Height measured in m = height in cm/100
- Reference Material: e.g. peer reviewed literature

The next stage of the project is to define how the defined data items will be stored within the BIRO Data Dictionary and how data items map to the indicators defined in Work Package 2. Also included will be the key information identified during the clinical review. This document clearly explains the calculations, translations, elements and mappings required for this purpose.

6. Clinical Review and Dataset Representation

Work Package 2 reviewed the published literature regarding the complications and observations regarding diabetes care and control. Key information was identified here that must be represented in the BIRO Data Dictionary.

Work Package 3 reviewed the existing datasets used by BIRO partners with the aim of identifying commonalities, discrepancies and a final, defined list of items suitable for use within the project. The following section identifies the relevant metadata that must be stored for browsing and review.

Individual Data Items

Parameter:	e.g. Height
BIRO Ref:	e.g. BIRO012
Field Name:	e.g. HEIGHT
Data Type:	e.g. Real (nnn.nn)
Definition:	e.g. Height in metres - measured without shoes. It is particularly important to measure regularly the height of children. In adults a single recording will usually be sufficient.
Units:	e.g. Metres
Lower Range:	e.g. 0.4
Upper Range:	e.g. 2.5
Mandatory:	e.g. No
Validity:	e.g. High
Data Mapping:	e.g. Height measured in m = height in cm/100

Clinical Indicators

Indicator Reference:	e.g. 71
Indicator Title:	e.g. Annual incidence of blindness in patients with diabetes (among those visited during the last 12 months)
Numerator:	e.g. Number of diabetes patients recorded to have become blind
Denominator:	e.g. Number of clinically diagnosed diabetes patients in the study region/country who visited during the last 12 months
Contributing Data Items:	e.g. BIRO001: PAT_ID, BIRO002: DS_ID, BIRO003: TYPE_DM, BIRO007: EPI_DATE, BIRO036: BLIND
Source(s):	e.g. EUDIP, modified in the BIRO meeting in Malta
Common Dataset Issues:	e.g. Blindness has Medium Validity: Scottish definition specifies clinical status, FQSD concerns compensation payments.
Comments:	e.g. N/A

Work Package 4: BIRO D4.1: Data Dictionary

References

Work Package 2 also identified key references associated with each data item. Again, these should be stored for further review in the data dictionary.

Parameter:	e.g. HbA1c
BIRO Ref:	e.g. BIRO016
References:	<p>e.g. Abraira C, Colwell J, Nuttall F, et al. Cardiovascular events and correlates in the Veterans Affairs Diabetes Feasibility Trial: Veterans Affairs Cooperative Study Group on Glycemic Control and Complications in Type II Diabetes. Arch Intern Med 1997;157:181-8</p> <p>Davis TME, Millns H, Stratton IM, et al. Risk Factors for Stroke in Type 2 Diabetes Mellitus. United Kingdom Prospective Diabetes Study (UKPDS) 29. Arch Intern Med 1999;159:1097-103</p> <p>The University Group Diabetes Program. Effects of hypoglycemic agents on vascular complications in patients with adult-onset diabetes. VIII: Evaluation of insulin therapy: final report. Diabetes 1982;31(Suppl. 5):1-26</p> <p>UK Prospective Diabetes Study (UKPDS) Group. Effect of intensive blood-glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34). Lancet 1998;352:854-65</p> <p>... etc</p>
Comments:	<p>e.g. Poor glycaemic control, obesity, lack of exercise, smoking, hyperinsulinemia, dyslipidemia and microalbuminuria are not significantly associated with stroke (Davis 1999). Intensive glycaemic control can delay the onset and the progression of diabetic retinopathy, nephropathy and neuropathy (Ohkubo 1995).</p> <p><i>EUDIP</i>: Many prospective studies demonstrate an association between a good metabolic control and a reduction in micro vascular (retinopathy, nephropathy neuropathy) and macro vascular (cardiovascular) complications (36-37)</p> <p><i>SIGN 55</i>: Hypoglycaemic events should be assessed.</p> <p>... etc</p>

7. Data Item Mappings

This section details how mapping information will be stored in the BIRO Data Dictionary. The various attributes assigned to each mapping will translate to elements in the BIRO Data Dictionary XML Schema.

Some systems contributing to the BIRO data analysis store clinical data in a format that is inconsistent to the BIRO dataset. In most cases, it is possible to map from the source data format to the BIRO format. It was agreed during the Common Dataset development that The International System of Units (SI) would be used as the standard storage format.

Derived Data

The following section details the precise mappings identified as being required to derive standard BIRO data items from non-standard units. A multiplication factor and a division factor will be available where relevant along with a precise mapping.

Field:	TYPE_DM
Standard BIRO Unit:	1 = Type 1
Non-Standard Unit:	IDDM
Multiplication Factor:	N/A
Division Factor:	N/A
Mapping Data:	IDDM = Type 1
Comments:	IDDM: Patients marked as having Insulin-Dependent Diabetes Mellitus should be classified as having Type 1 Diabetes

Field:	TYPE_DM
Standard BIRO Unit:	2 = Type 2
Non-Standard Unit:	NIDDM
Multiplication Factor:	N/A
Division Factor:	N/A
Mapping Data:	NIDDM = Type 2
Comments:	NIDDM: Patients marked as having Non Insulin-Dependent Diabetes Mellitus should be classified as having Type 2 Diabetes

Field:	DOB
Standard BIRO Unit:	ccyy-01-01
Non-Standard Unit:	ccyy-mm-dd
Multiplication Factor:	N/A
Division Factor:	N/A
Mapping Data:	ccyy-mm-dd = ccyy-01-01
Comments:	Only year of birth necessary at present, not full date

Field:	DT_DIAG
Standard BIRO Unit:	ccyy-01-01
Non-Standard Unit:	ccyy-mm-dd
Multiplication Factor:	N/A
Division Factor:	N/A
Mapping Data:	ccyy-mm-dd = ccyy-01-01
Comments:	Only year of diagnosis necessary at present, not full date

Field:	EPI_DATE
Standard BIRO Unit:	Date of recording
Non-Standard Unit:	Recording in last year (DiabCare)
Multiplication Factor:	N/A
Division Factor:	N/A
Mapping Data:	Review Date = EPI_DATE
Comments:	For datasets such as DiabCare where a date of result is not recorded for each individual data item, but it is known that the result was recorded in the last year, the associated date will be recorded as the review date. This is to allow these datasets to contribute to indicators detailing results “recorded in the last 12 months”.

Field:	ALCOHOL
Standard BIRO Unit:	Units/week
Non-Standard Unit:	Grams/week
Multiplication Factor:	N/A
Division Factor:	10
Mapping Data:	1 unit of alcohol = 10g
Comments:	

Field:	HEIGHT
Standard BIRO Unit:	Metres
Non-Standard Unit:	Centimetres
Multiplication Factor:	N/A
Division Factor:	100
Mapping Data:	Height measured in m = height in cm/100
Comments:	

Field:	CREAT
Standard BIRO Unit:	µmol/l
Non-Standard Unit:	mg/dl
Multiplication Factor:	N/A
Division Factor:	0.0131
Mapping Data:	µmol/l = mg/dl / 0.0131
Comments:	

Field:	CHOL
Standard BIRO Unit:	mmol/L
Non-Standard Unit:	mg/dl
Multiplication Factor:	N/A
Division Factor:	38.61
Mapping Data:	mmol/L = mg/dl / 38.61
Comments:	

Field:	HDL
Standard BIRO Unit:	mmol/L
Non-Standard Unit:	mg/dl
Multiplication Factor:	N/A
Division Factor:	38.61
Mapping Data:	mmol/L = mg/dl / 38.61
Comments:	

Field:	LDL
Standard BIRO Unit:	mmol/L
Non-Standard Unit:	mg/dl
Multiplication Factor:	N/A
Division Factor:	38.61
Mapping Data:	mmol/L = mg/dl / 38.61
Comments:	

Field:	TG
Standard BIRO Unit:	mmol/L
Non-Standard Unit:	mg/dl
Multiplication Factor:	N/A
Division Factor:	38.61
Mapping Data:	mmol/L = mg/dl / 38.61
Comments:	

Calculated Data

The following section details the BIRO data items that can be calculated using other items in the dataset to make a new variable.

Field:	BMI
Standard BIRO Unit:	Kg/m ²
Contributing Items:	HEIGHT, WEIGHT
Mapping Data:	weight(kg)/height(m) ²
Comments:	Not an explicitly listed field in DiabCare, but can be easily calculated using weight and height

8. Indicator Calculations

BIRO Work Package 3, Appendix 3 details the data items required to fulfil the requirements of each indicator. The Clinical Review also identified the numerator and denominator required to calculate these. This section of deliverable 4.1 takes this one step further by explaining the pseudo code calculations required to create the data, explicitly detailing the items to be used from the defined dataset.

Reference No:	1
Indicator:	Annual Incidence of Type 1 Diabetes in children between 0 – 14 years of age at diagnosis (clinical) per 100,000 children
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO005: DOB BIRO104: DS_DENOM
Calculation:	Total Patients (PAT_ID) / (Data Source Denominator (DS_DENOM) / 100000) With Type 1 Diabetes (TYPE_DM = 1) Grouped By Year of Birth (in DOB) and Data Source ID (DS_ID)
Output:	Number of Type 1 patients/100000 grouped by year and by data source. Reference to age bandings defined in section 8 of this document.
Source:	EUDIP

Reference No:	4
Indicator:	Prevalence of diabetes mellitus per 1,000
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO104: DS_DENOM
Calculation:	Total Patients (PAT_ID) / (Data Source Denominator (DS_DENOM) / 1000) With Any Type of Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Number of patients with diabetes per 1000 grouped by data source.
Source:	EUDIP

Reference No:	17
Indicator:	Age at diagnosis by 10 year age bands (incidence)
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO005: DOB BIRO006: DT_DIAG BIRO104: DS_DENOM
Calculation:	Total Patients (PAT_ID) / Data Source Denominator (DS_DENOM) With Any Type of Diabetes (TYPE_DM IN (1, 2, 3)) Grouped by 10 Year Age Band (compare DOB and DT_DIAG) and Data Source (DS_ID)
Output:	Number of patients and their age at diagnosis grouped by ten year age bands and data source.
Source:	EUDIP

Reference No:	19
Indicator:	Hospital beds per 100,000 population
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO116: DS_BEDS
Calculation:	Hospital Beds (DS_BEDS) / (Data Source Denominator (DS_DENOM) / 100000) Grouped by DataSource (DS_ID)
Output:	Number of hospital beds per 100000 of regional population grouped by data source.
Source:	ECHI

Reference No:	20
Indicator:	Physicians employed per 100,000 population
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO117: DS_PHYSICIANS
Calculation:	Physicians (DS_PHYSICIANS) / (Data Source Denominator (DS_DENOM) / 100000) Grouped by DataSource (DS_ID)
Output:	Number of physicians employed per 100000 of regional population grouped by data source.
Source:	ECHI

Reference No:	21
Indicator:	Number of diabetologists per 100,000
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO118: DS_DIABETOLOGISTS
Calculation:	Diabetologists (DS_Diabetologists) / (Data Source Denominator (DS_DENOM) / 100000) Grouped by DataSource (DS_ID)
Output:	Number of diabetologists employed per 100000 of regional population grouped by data source.
Source:	Joanneum

Reference No:	22
Indicator:	Number of doctors who regularly take care of diabetic patients in diabetes clinics in primary or secondary care per 100,000
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO119: DS_DOCTORS
Calculation:	Doctors (DS_DOCTORS) / (Data Source Denominator (DS_DENOM) / 100000) Grouped by DataSource (DS_ID)
Output:	Number of diabetic doctors per 100000 of regional population grouped by data source.
Source:	BIRO

Reference No:	24
Indicator:	Number of diabetes nurses employed per 100,000
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO120: DS_DSN
Calculation:	Diabetes Specialist Nurses (DS_DSN) / (Data Source Denominator (DS_DENOM) / 100000) Grouped by DataSource (DS_ID)
Output:	Number of diabetes specialist nurses per 100000 of regional population grouped by data source.
Source:	ECHI

Reference No:	25
Indicator:	Number of structured Disease Management Programmes
Contributing Data Items:	BIRO002: DS_ID BIRO104: DS_DENOM BIRO121: DS_PROGS
Calculation:	Disease Management Programmes (DS_PROGS) Grouped by DataSource (DS_ID)
Output:	Number of disease management programmes active grouped by data source.
Source:	Joanneum

Reference No:	27
Indicator:	Percentage with one or more HbA1c tests during the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO016: HBA1C
Calculation:	Total Patients (PAT_ID) with valid HbA1c result (HBA1C) in last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with valid HbA1c result in last 12 months grouped by data source.
Source:	OECD

Reference No:	28
Indicator:	Percentage of patients with one or more Total cholesterol/HDL tests during the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO019: CHOL BIRO020: HDL
Calculation:	Total Patients (PAT_ID) with valid Total Cholesterol (CHOL) or HDL (HDL) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with valid Cholesterol or HDL result in last 12 months grouped by data source.
Sources:	EUDIP OECD

Reference No:	29
Indicator:	Percentage of patients with at least one test for microalbuminuria during the measurement year or who had evidence of medical attention for existing nephropathy
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO018: MA_TEST BIRO028: ESRF BIRO029: DIALYSIS BIRO030: TRANSPLANT
Calculation:	Total Patients (PAT_ID) with MA Test (MA_TEST = 1 or 2) within the last 12 months (EPI_DATE) and (having End Stage Renal Failure (ESRF) or having Renal Dialysis (DIALYSIS) or had Renal Transplant (TRANSPLANT)) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with test for microalbuminuria in last 12 months who have evidence of existing nephropathy grouped by data source.
Source:	OECD

Reference No:	30
Indicator:	Percentage of diabetes patients who received a dilated eye examination or evaluation of retinal photography by a trained caregiver within the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO022: RETINAL_EXAM
Calculation:	Total Patients (PAT_ID) with eye examination (RETINAL_EXAM) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with a retinal examination within the last 12 months grouped by data source.
Source:	OECD, modified by BIRO

Reference No:	31
Indicator:	Percentage of diabetes patients receiving at least one foot examination within the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO025: FOOT_EXAM
Calculation:	Total Patients (PAT_ID) with foot examination (FOOT_EXAM) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with a foot examination within the last 12 months grouped by data source.
Source:	OECD

Reference No:	32
Indicator:	Percentage of diabetes patients whose smoking status was ascertained and documented within the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO008: SMOK_STAT
Calculation:	Total Patients (PAT_ID) with foot examination (SMOK_STAT = 1, 2 or 3) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with a smoking status record within the last 12 months grouped by data source.
Source:	OECD

Reference No:	34
Indicator:	Percent with serum creatinine tested in last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO017: CREAT
Calculation:	Total Patients (PAT_ID) with creatinine (CREAT) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with a creatinine record within the last 12 months grouped by data source.
Source:	EUDIP

Reference No:	35
Indicator:	Percentage of patients with diabetes and one or more blood pressure measurements within the last 12 months
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO014: SBP BIRO015: DBP
Calculation:	Total Patients (PAT_ID) with blood pressure (SBP and/or DBP) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with a blood pressure record within the last 12 months grouped by data source.
Source:	EUDIP

Reference No:	36
Indicator:	Percentage of patients with hypertension who receive hypertensive medication
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO035: HYPERTENSION BIRO038: HYPERT_MED
Calculation:	Total Patients (PAT_ID) with hypertension (HYPERTENSION) who receive hypertension medication (HYPERT_MED) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with hypertension who receive hypertension medication grouped by data source.
Source:	Joanneum

Reference No:	38
Indicator:	Percentage of patients with diabetes specific education at least once before
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO045: EDUCATION
Calculation:	Total Patients (PAT_ID) who have received diabetes specific education (EDUCATION) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients who have received diabetes education grouped by data source.
Source:	Joanneum

Reference No:	40
Indicator:	Type of oral therapy (distribution of agents) in patients with diabetes type 2
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO040: ORAL_THERAPY
Calculation:	Total Patients (PAT_ID) / Total Patients (PAT_ID) With Type 2 Diabetes (TYPE_DM = 2) Grouped by Type of Oral Therapy (ORAL_THERAPY) and Data Source (DS_ID)
Output:	Percentage of patients with Type 2 diabetes grouped by type of oral therapy and data source
Source:	Joanneum

Reference No:	41
Indicator:	Portion of patients treated with insulin among patients with diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO039: DRUG_THERAPY
Calculation:	Total Patients (PAT_ID) treated with insulin (DRUG_THERAPY = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients treated with insulin grouped by data source
Source:	Joanneum

Reference No:	42
Indicator:	Portion of patients treated with insulin in combination with OADs among patients with diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO039: DRUG_THERAPY
Calculation:	Total Patients (PAT_ID) treated with insulin and tablets (DRUG_THERAPY = 3) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients treated with insulin and tablets grouped by data source
Source:	Joanneum

Reference No:	44
Indicator:	Percentage of insulin treated patients with pump therapy
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO039: DRUG_THERAPY BIRO041: PUMP_THERAPY
Calculation:	Total Patients (PAT_ID) treated with insulin (DRUG_THERAPY = 1 or 3) who receive Pump Therapy (PUMP_THERAPY = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients treated with insulin who receive pump therapy grouped by data source
Source:	BIRO

Reference No:	45
Indicator:	Average number of insulin injections per day in insulin treated patients
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO039: DRUG_THERAPY BIRO043: INJECTIONS
Calculation:	Average Injections (INJECTIONS) with Patients (PAT_ID) treated with insulin (DRUG_THERAPY = 1 or 3) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Average number of injections amongst insulin treated patients, grouped by data source
Source:	BIRO

Reference No:	49
Indicator:	Portion of diabetes patients with anti hypertensive treatment
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO038: HYPERT_MED
Calculation:	Total Patients (PAT_ID) treated with hypertensive medication (HYPERT_MED) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients treated with hypertensive medication grouped by data source
Source:	Joanneum

Reference No:	51
Indicator:	Percent of patients with diabetes performing self-monitoring of blood glucose/ urine testing
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO044: SELF_MON
Calculation:	Total Patients (PAT_ID) performing self monitoring (SELF_MON = 1, 2 or 3) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients performing self monitoring grouped by data source
Source:	Joanneum

Reference No:	54
Indicator:	Percentage of patients with most recent HbA1c level >9.0% (poor control)
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO016: HBA1C
Calculation:	Total Patients (PAT_ID) with latest HbA1c result >9.0 (HBA1C and EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with latest HbA1c result greater than 9.0% grouped by data source.
Source:	OECD

Reference No:	55
Indicator:	Percentage of patients with most recent HbA1c level >7.5%
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO016: HBA1C
Calculation:	Total Patients (PAT_ID) with latest HbA1c result >7.5 (HBA1C and EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with latest HbA1c result greater than 7.5% grouped by data source.
Source:	OECD

Reference No:	57
Indicator:	Percentage of patients with Total-Chol / HDL-Chol < 4.5
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO019: CHOL BIRO020: HDL
Calculation:	Total Patients (PAT_ID) with latest Cholesterol (CHOL and EPI_DATE) or HDL (HDL and EPI_DATE) result < 4.5 / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with latest cholesterol or HDL result less than 4.5% grouped by data source.
Source:	Dundee

Reference No:	58
Indicator:	Percentage of patients with most recent blood pressure <140/90 mmHg
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO014: SBP BIRO015: DBP
Calculation:	Total Patients (PAT_ID) with latest Blood Pressure (SBP, DBP and EPI_DATE) < 140/90 / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with latest Blood Pressure result less than 140/90 grouped by data source.
Source:	OECD

Reference No:	60
Indicator:	Percentage of patients with BMI >= 30
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO013: BMI
Calculation:	Total Patients (PAT_ID) with latest Body Mass Index (BMI and EPI_DATE) >= 30 / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients with latest Boddy Mass index result greater than or equal to 30 grouped by data source.
Source:	EUDIP

Reference No:	61
Indicator:	Percentage of patients with waist circumference above IDF cut-offs
Calculation:	Waist circumference has not been included in the BIRO Common Dataset as it does not currently appear in either the Scottish or DiabCare datasets – to be reviewed.

Reference No:	62
Indicator:	Percentage of persons with diabetes mellitus with a fundus inspection in the last 12m, who have proliferative retinopathy and/or maculopathy
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO022: RETINAL_EXAM BIRO023: RETINA BIRO024: MACULA
Calculation:	Total Patients (PAT_ID) with proliferative retinopathy (RETINA = 2) and/or maculopathy (MACULA = 1) who have had an eye examination (RETINAL_EXAM) result within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with referable retinopathy and/or referable maculopathy who have had a retinal examination within the last 12 months, grouped by data source.
Source:	EUDIP

Reference No:	64
Indicator:	Percentage of patients with laser treatment ever
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO034: LASER
Calculation:	Total Patients (PAT_ID) with laser treatment (LASER = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with laser treatment ever, grouped by data source.
Source:	Joanneum

Reference No:	65
Indicator:	Percentage with microalbuminuria in last 12 months (among those who have been tested)
Calculation:	Total Patients (PAT_ID) with microalbuminuria (MA_TEST = 2) within the last 12 months (EPI_DATE) / Total Patients (PAT_ID) tested for microalbuminuria (MA_TEST = 1 or 2) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with abnormal microalbuminuria test amongst those tested within the last 12 months, grouped by data source.
Source:	BIRO

Reference No:	66
Indicator:	Rate of current smokers amongst diabetes patients
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO008: SMOK_STAT
Calculation:	Total Patients (PAT_ID) whose latest smoking assessment (EPI_DATE) indicates that they smoke (SMOK_STAT = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients who currently smoke, grouped by data source.
Source:	Joanneum

Reference No:	67
Indicator:	Rate of patients with current alcohol abuse/dependence
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO010: ALCOHOL
Calculation:	Total Patients (PAT_ID) whose latest alcohol intake assessment (EPI_DATE) indicates that they currently abuse alcohol (ALCOHOL > 30 units / week) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients who currently consume more than 30 units of alcohol per week, grouped by data source.
Source:	Joanneum

Reference No:	69
Indicator:	Former or current foot ulceration
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO032: ULCER
Calculation:	Total Patients (PAT_ID) with history of foot ulcer (ULCER = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of patients with foot ulcer ever, grouped by data source.
Source:	Joanneum

Reference No:	71
Indicator:	Annual incidence of blindness in patients with diabetes (among those visited during the last 12 months)
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO036: BLIND
Calculation:	Total Patients (PAT_ID) with first recording of blindness (BLIND = 1 and EPI_DATE) in last 12 months / Total Patients (PAT_ID) who had an assessment within last 12 months (EPI_DATE) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by Data Source (DS_ID)
Output:	Percentage of diabetic patients who were diagnosed as being blind among those who visited within last 12 months, grouped by data source.
Source:	EUDIP, modified by BIRO

Reference No:	73
Indicator:	Annual incidence of dialysis and/or transplantation (renal replacement therapy) in patients with diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO029: DIALYSIS BIRO030: TRANSPLANT
Calculation:	Total Patients (PAT_ID) with renal dialysis (DIALYSIS = 1) or transplant (TRANSPLANT = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by year of incidence (in EPI_DATE) and Data Source (DS_ID)
Output:	Percentage of diabetic patients who had renal dialysis or transplant, grouped by incidence year and data source.
Source:	Joanneum

Reference No:	74
Indicator:	ESRD in Persons with Diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO028: ESRF
Calculation:	Total Patients (PAT_ID) with End Stage Renal Failure (ESRF = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by year of incidence (in EPI_DATE) and Data Source (DS_ID)
Output:	Percentage of diabetic patients who had end stage renal failure, grouped by incidence year and data source.
Source:	OECD

Reference No:	75
Indicator:	Annual incidence of amputations above the ankle
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO037: AMPUTATION
Calculation:	Total Patients (PAT_ID) with Amputation (AMPUTATION = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by year of incidence (in EPI_DATE) and Data Source (DS_ID)
Output:	Percentage of diabetic patients who had an amputation, grouped by incidence year and data source.
Source:	OECD EUDIP

Reference No:	76
Indicator:	Annual incidence of stroke in patients with diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO031: STROKE
Calculation:	Total Patients (PAT_ID) with Stroke (STROKE = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by year of incidence (in EPI_DATE) and Data Source (DS_ID)
Output:	Percentage of diabetic patients who had a stroke, grouped by incidence year and data source.
Source:	Joanneum

Reference No:	78
Indicator:	Annual Incidence of myocardial infarction in patients with diabetes
Contributing Data Items:	BIRO001: PAT_ID BIRO002: DS_ID BIRO003: TYPE_DM BIRO007: EPI_DATE BIRO033: MI
Calculation:	Total Patients (PAT_ID) with myocardial infarction (MI = 1) / Total Patients (PAT_ID) With Diabetes (TYPE_DM = 1, 2 or 3) Grouped by year of incidence (in EPI_DATE) and Data Source (DS_ID)
Output:	Percentage of diabetic patients who had a myocardial, grouped by incidence year and data source.
Source:	Joanneum

Reference No:	80
Indicator:	Annual death rate per 100,000 populations in the general population from all causes, adjusted for standard European population
Calculation:	Death not recorded in DiabCare – to be reviewed

9. Age Bandings

Within BIRO, several indicators will be required to group patients into age ranges for comparison purposes. To maintain consistency with the existing EUCID project, BIRO will use the same ranges. These are as follows:

Band ID:	BAND1
Lower Range:	0
Upper Range:	14

Band ID:	BAND2
Lower Range:	15
Upper Range:	24

Band ID:	BAND3
Lower Range:	25
Upper Range:	34

Band ID:	BAND4
Lower Range:	35
Upper Range:	44

Band ID:	BAND5
Lower Range:	45
Upper Range:	54

Band ID:	BAND6
Lower Range:	55
Upper Range:	64

Band ID:	BAND7
Lower Range:	65
Upper Range:	74

Band ID:	BAND8
Lower Range:	75
Upper Range:	84

Band ID:	BAND9
Lower Range:	85
Upper Range:	None

10. Defining Data Quality and Consistency Issues

In order to explain the comparability of data across all BIRO partners, data quality issues must be fully documented and visible to the end-users of the BIRO system. This information is a key requirement for the statistical analysis and to explain variations between sites for each of the defined indicators. This section will cover the data that must be gathered to meet this requirement.

Data Item Assessment

For each item in the BIRO dataset, each partner will be required to assess its quality in comparison with the agreed definitions. Although not an insignificant piece of work, this information will provide substantial metadata describing the feeding systems and will contribute considerably to the interpretation of the indicators. This will make the BIRO outcomes unrivalled in terms international data analysis.

A number of criteria must be applied to the data items by each partner. This assessment exercise must detail:

- Consistency with the BIRO definition
 - High: Exact match
 - Medium: Minor discrepancy – e.g. Source units require mapping
 - Low: Major discrepancy – e.g. mapping unavailable
 - Data Item Unavailable
- Completeness
 - Complete: Full data available for all currently diagnosed patients
 - Incomplete: Partial data available for all currently diagnosed patients
 - Data Item Unavailable
- Overall Quality Score: a value judgement on the ability for the data source to provide complete and consistent data in line with the definition
 - High: Can provide complete and consistent data
 - Medium: Minor completeness and consistency issues
 - Low: Major completeness and consistency issues
 - Data Item Unavailable
- Comments: This field should be used to describe any further information known about the data item at source that may affect longitudinal analysis or data presentation

The example below explains the submission for the 'HBA1C' field within the DARTS dataset in Tayside, Scotland.

Data Item:	HBA1C
Consistency:	High
Completeness:	Complete
Quality Score:	High
Comments:	In Tayside, HbA1c was DCCT aligned in August 2002.

This information is a key area of knowledge and may be displayed alongside BIRO outputs and statistics. A mock-up showing how this may look on the final website is given below.

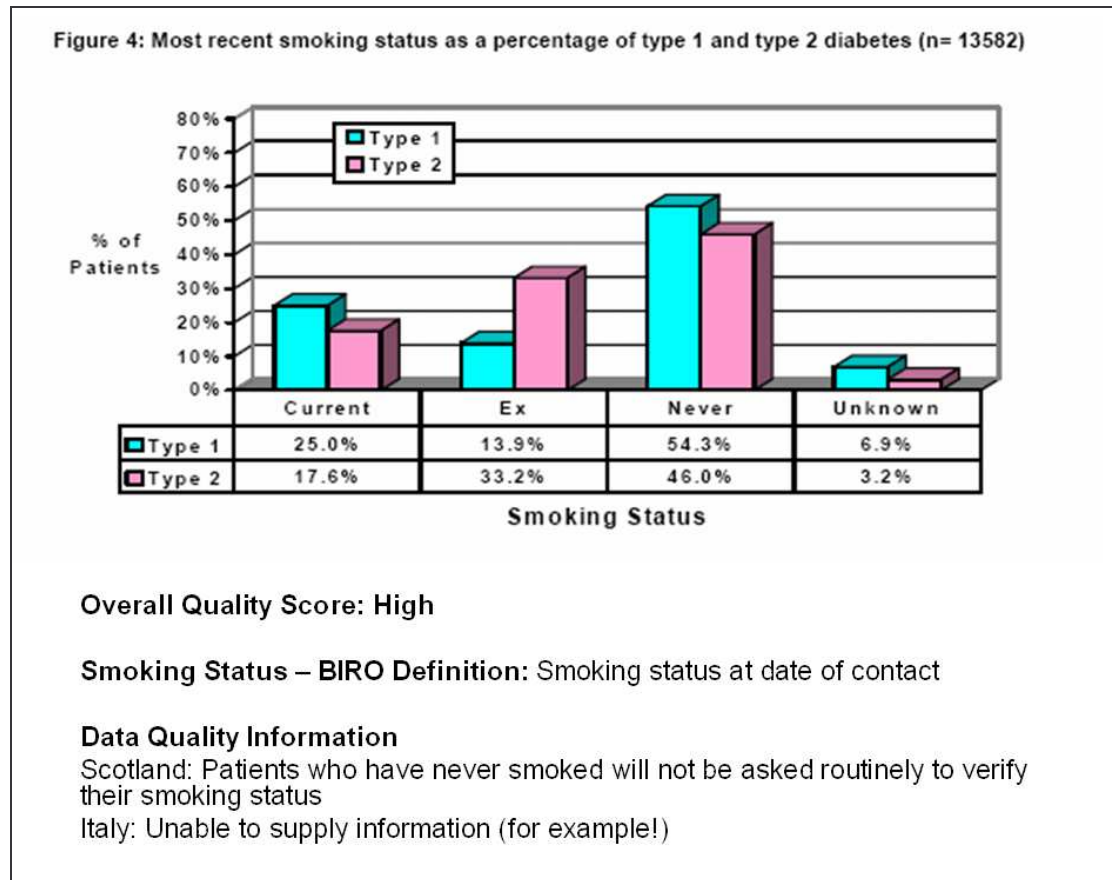


Figure 1: Example Output Showing Data Quality Information

It should also be possible to ‘drill-down’ and view the data quality information supplied by each data source for the contributing data items for the indicator.

11. Browsing the BIRO Data Dictionary

The key objective of BIRO is to allow the automated comparison of national Diabetes indicators across Europe. In addition to this it is also desirable to browse the BIRO dataset and data dictionary defined in Work Packages 3 and 4 to gain an understanding of the data collected. This chapter aims to show examples of existing data dictionary and data standards resources that allow the end user to browse the dataset and associated metadata.

Existing Data Dictionaries

In the UK, there has been a longstanding approach to the development of datasets. The Scottish Intercollegiate Guidelines Network published their first minimum dataset for people with Diabetes in 1998 in SIGN 25. Since then, NHS Scotland has developed the National Clinical Datasets Development Programme which now allows now holds the current datasets across all specialties online.

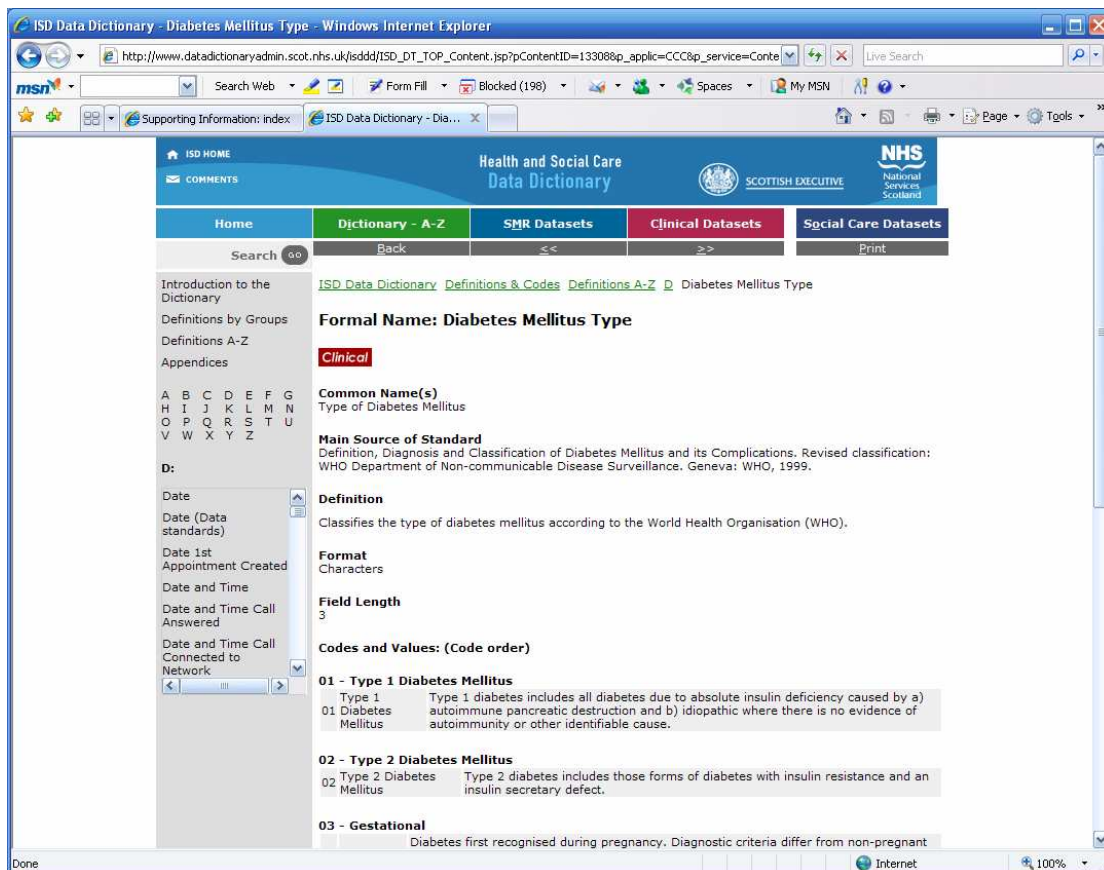


Figure 2: NHS Scotland Health and Social Care Data Dictionary

In addition to allowing the user to search for, and to browse the details of every single data item within these datasets, all related metadata is also made available to the user. It is expected that the BIRO website would provide similar functionality containing the content defined in this document, and the

Work Package 4: BIRO D4.1: Data Dictionary

contents supplied by each of the partner institutions detailing the intricacies of their data.

The NHS in England and Wales (<http://www.datadictionary.nhs.uk/>) and Australian Institute of Health and Welfare Metadata Online Registry (<http://meteor.aihw.gov.au/content/index.phtml/itemId/276533>) provide similar resources, and many more examples are available online: