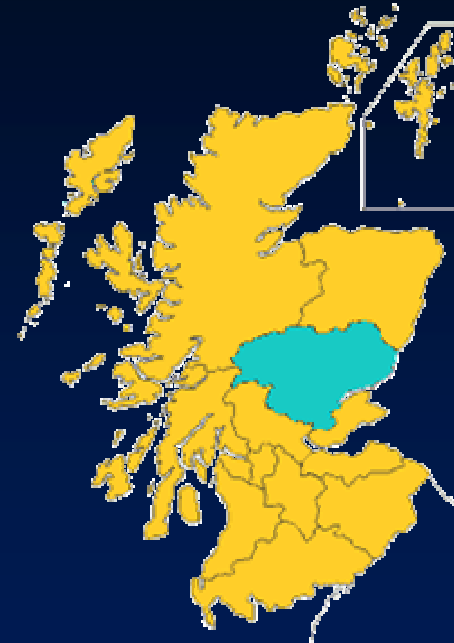


Work Package 3: Common Dataset

Work Package 4: Data Dictionary



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The DARTS / MEMO Collaboration

Introduction

- Progress to Date
- Initial Dataset
- Parameters
- Clinical Sites
- Quality Criteria
- Linking to Indicators
- META Data

Work Package 3: Common Dataset

- “The WP will ensure the definition of a minimum dataset that can be used as a common data reference for the extraction of compatible entities at the international level.”
- “A coding/decoding mechanism will be identified to translate regional data in entities that can contribute to the definition of a shared information system.”

Work Package 4: Data Dictionary

- “The WP will create an electronic directory inclusive of concept and data dictionaries for diabetes care and prevention, thereby allowing to dynamically link the clinical knowledge-base to the systematic evaluation of health systems outcomes.”

Progress to Date

- Dataset comparison
 - DiabCare
 - Scottish Diabetes Core Dataset
 - Umbria AMD Data File
 - EUCID
- [BIRO Dataset Comparison_V2_0.xls](#)

Core Data Items

- 25 High Validity Data Items Identified
- Basic Patient Information
 - e.g. Type of Diabetes, Date of Birth, Year of Diagnosis
- **Risk Factors**
 - e.g. Cigarettes / Day
- **Clinical Measurements**
 - e.g. Weight, Height, SBP, DBP, HbA1c, Creatinine
- **Examinations**
 - e.g. Eye Examinations
- **Outcomes**
 - e.g. End Stage Renal Failure

Additional Data Items

- Additional analysis to identify items that can be gathered well by 2 or more partners
- Need to carefully select data items not present in EUDIP shortlist
- BIRO Dataset will contain data items broken down to following categories:
 - **High Validity (already defined)**
 - **Medium Validity**
 - **Low Validity**

Clinical Data Item Definitions

- DiabCare data items do not have clear definitions
- Concept of collecting data “Before” and “After” a visit or treatment is not easily defined
- Are FQSD definitions used across Europe?
- Dundee need details of all local definitions
- Statistics on completeness of data required

Clinical Site Data

- Need items in BIRO to describe clinical sites
- Country
- Data Source Type
 - e.g. GP, Hospital Clinic (Diabetes), Regional Register
- Name of Clinic
- Clinic Denominator (Population)
- Geographical Area
- Website

Clinical Site Data

- Contact Address
- Clinical Contact
- Clinical Contact Email Address
- Technical Contact
- Technical Contact Email Address
- We need this information from all partners for all sites!

Parameters

- Each BIRO Dataset item will be recorded as a “Parameter”
- Parameters will have a unique reference
- Will be clearly defined
- Will have an associated data type
- May have a unit of measurement (e.g.kg/m²)
- May have an upper or lower range
- May have a locally defined guideline value

Quality Criteria

- Quality Criteria can be applied to any data item from any data source
- QC1: All data for this item should be complete and accurate for all patient encounters
- QC2: Data is not routinely collected
- QC3: Data is only collected for a subset of the population
- QC4: The data is entered immediately by the medical staff

Quality Criteria

- QC5: The data is entered retrospectively by medical staff
- QC6: The data is entered retrospectively by administrative staff
- QC7: The laboratory analyser is not standardised for this test
- QC8: The results are estimates only
- Other suggestions required from all partners!
 - [Additional Quality Criteria.doc](#)

Indicators

- Work Packages 2, 3 and 4 will work closely
- Indicators must contain data items that are currently recorded consistently
- Indicators can be relevant at different levels
 - Health System Level
 - Provider Level
 - Patient Level
- Data from sites with certain quality criteria issues may be excluded from analyses

Indicators

- META Data for each Indicator will contain:
 - Full text description
 - Indicator level
 - Contributing parameters
 - Acceptable quality criteria
 - Acceptable clinical site types

META Data

- Parameters, Quality Criteria, Indicator and Clinical Sites shown in META Data Documentation
 - [BIRO Metadata v1 2.xls](#)
- Guidance Documentation
 - [BIRO Metadata Guidance v1 1.doc](#)

XML Schema

- BIRO META data will be sent to SEDIS engine in XML format
- Clinical Definitions for BIRO parameters
 - [ClinicalDefinitions.xml](#)
- Example Hospital Extract
 - [Ninewells_Data_Extract.xml](#)
- Open source XML software to be identified!

Summary

- From all partners, we require:
 - Local data definitions
 - Additional Quality Criteria
 - Descriptions of Clinical Sites