Best Information through Regional Outcomes

Population-based diabetes registers

Svein Skeie MD PhD
NOKLUS/The Norwegian Diabetes Registry for adults
Bergen, Norway

"A Shared Information System for Diabetes in Europe:
final results of the B.I.R.O. Project"
Dessau Conference Room
Perugia, 25 May 2009

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Questions for Policy and Practice

You cannot manage what you cannot measure

Can you improve what you cannot manage?

Best Information through Regional Outcomes

Population-based diabetes registers

"*It has been recommended that regional diabetes registers are established in the United Kingdom to facilitate systematic, population based monitoring of outcomes of diabetes and to ensure that diabetes care is effective, efficient, and equitable*"

[The report of the Joint Department of Health and British Diabetic Association Task Force for Diabetes. London: Department of Health, British Diabetic Association, 1995]

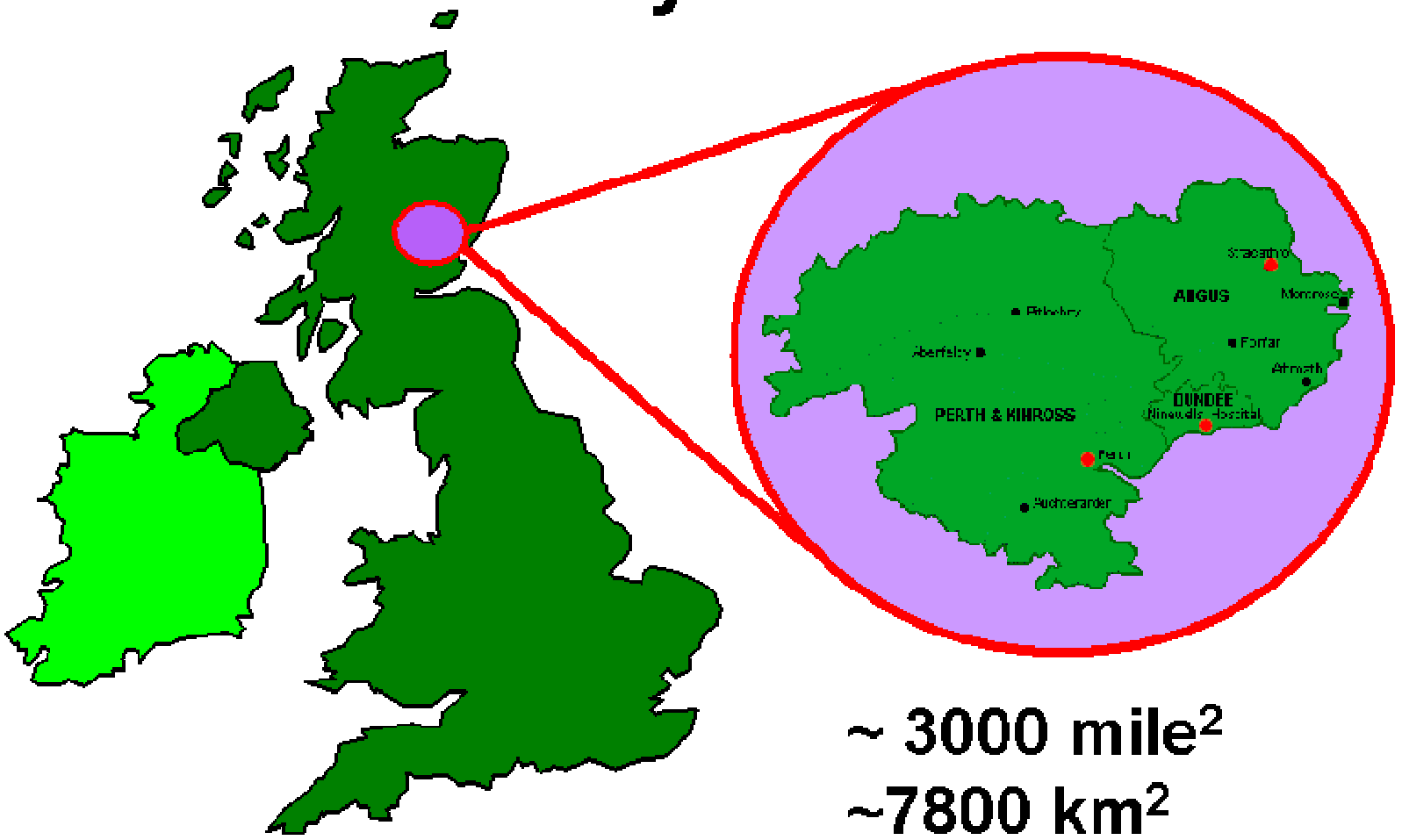
How should we treat diabetes?

- Early diagnosis
- Prevent vascular complications
  - treat risk factors
- Diagnose and treat complications early

Case Study: Scotland

Source: R.McAlpine, Tayside Diabetes Network

Tayside



~ 3000 mile²

~7800 km²

Progressive transition

Source: R.McAlpine, Tayside Diabetes Network

Research	Local Clinical Network	National Clinical Network
DARTS	Tayside Regional Diabetes Network (TRDN)	Scottish Care Information - Diabetes Collaboration (SCI-DC)

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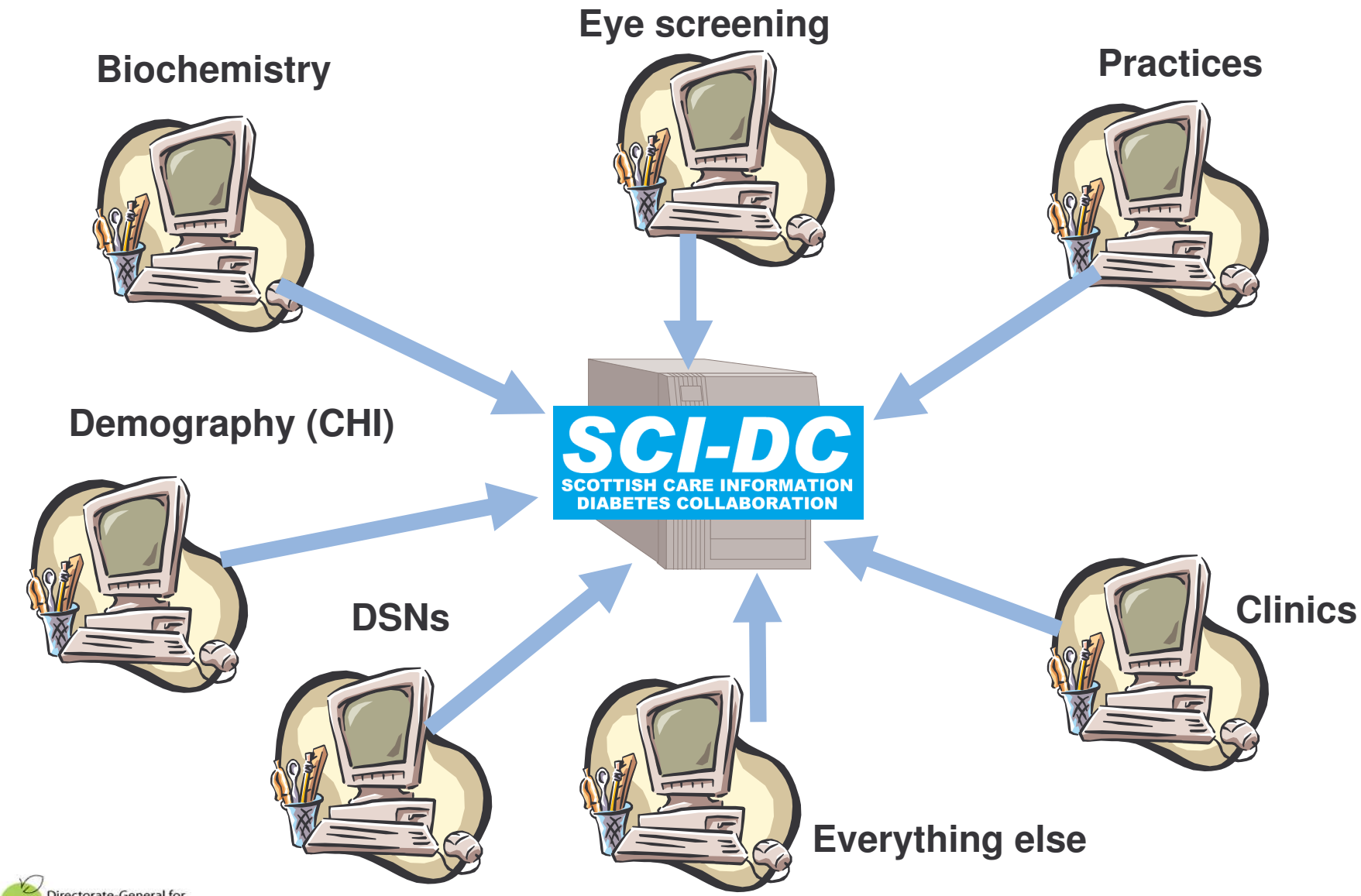
Complete data flow

Source: R.McAlpine, Tayside Diabetes Network



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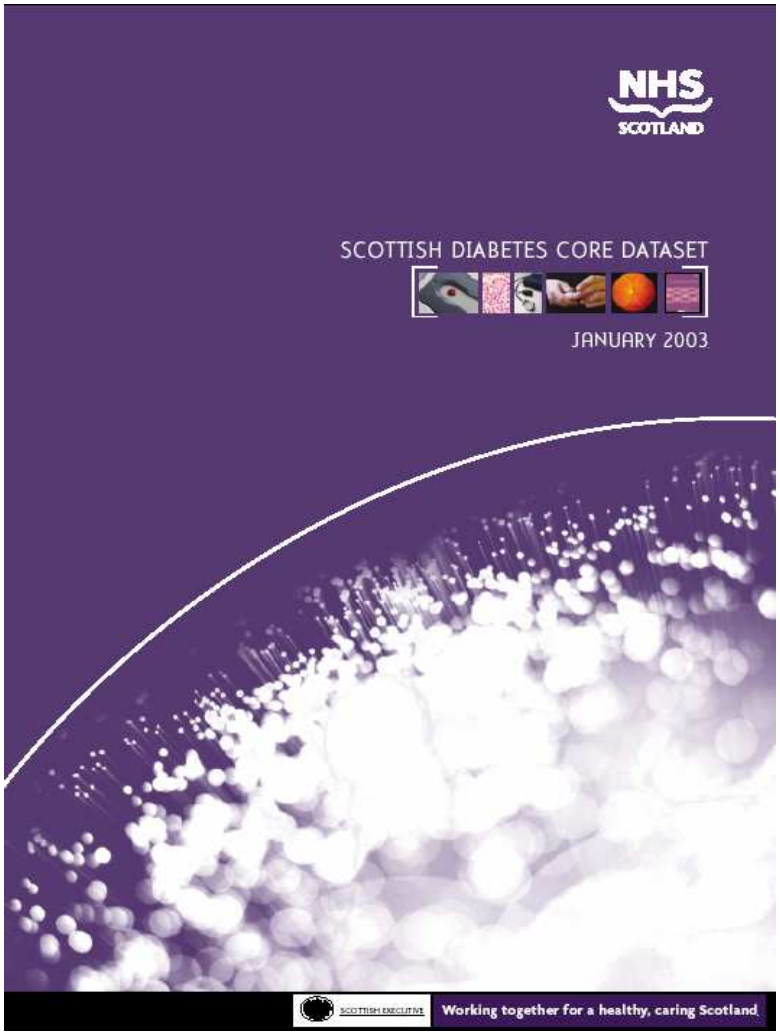
Case Study: Scotland

Source: S.Cunningham, Tayside Diabetes Network

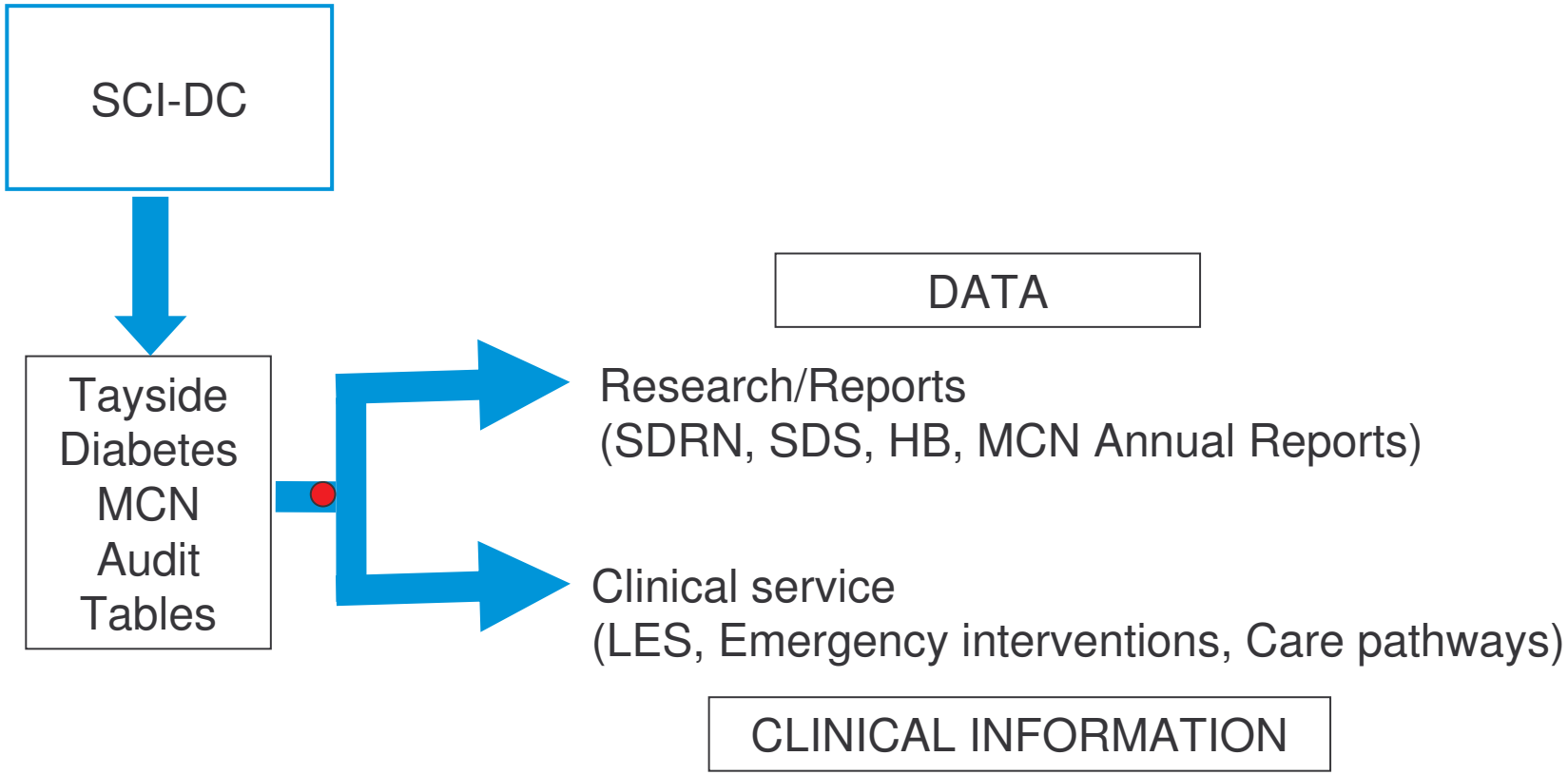
COMMON LANGUAGE

- Standardised dictionary of terms
- Clear and unambiguous clinical definitions



Information Split

Source: R.McAlpine, Tayside Diabetes Network



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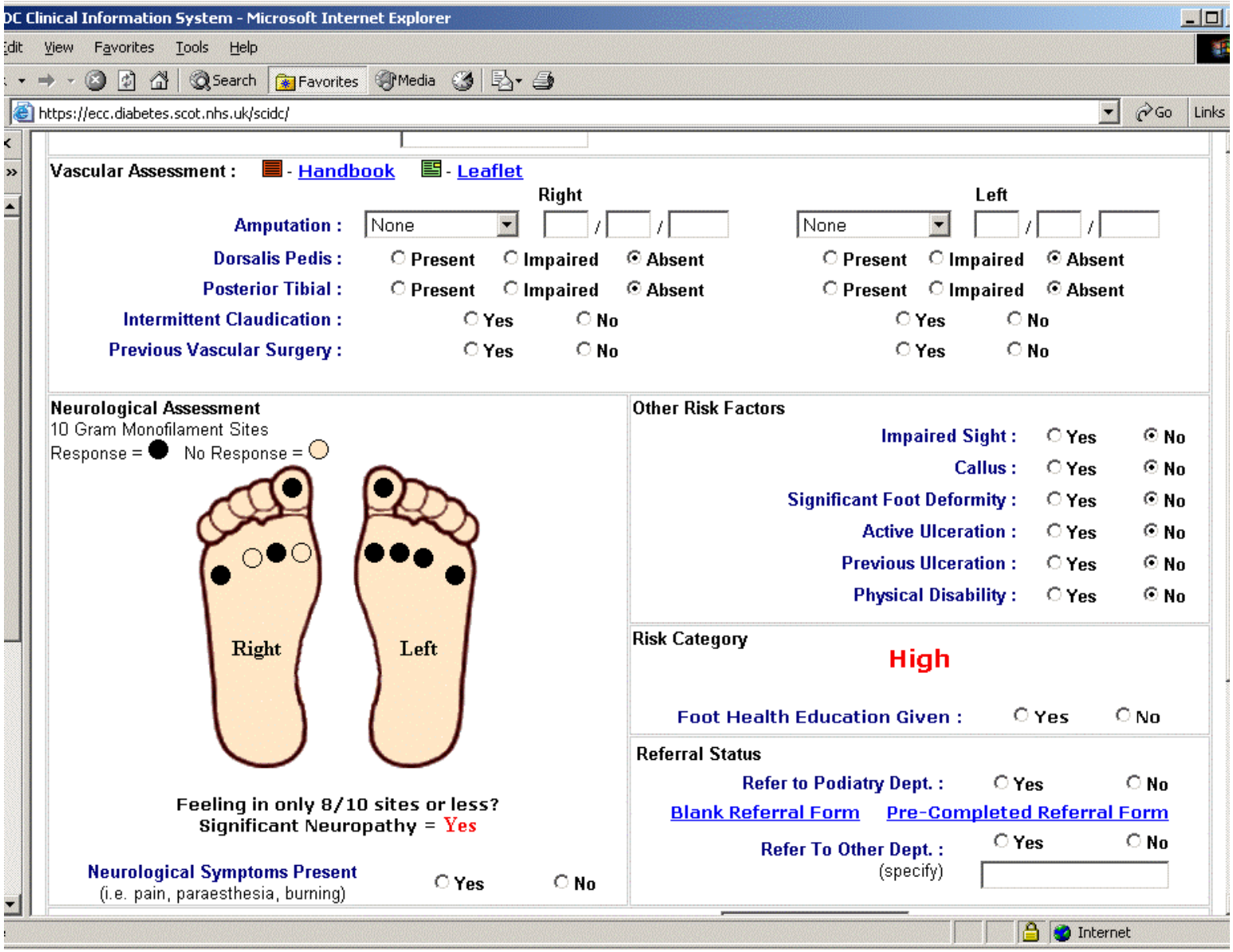
Local Enhanced Service

Source: R.McAlpine, Tayside Diabetes Network



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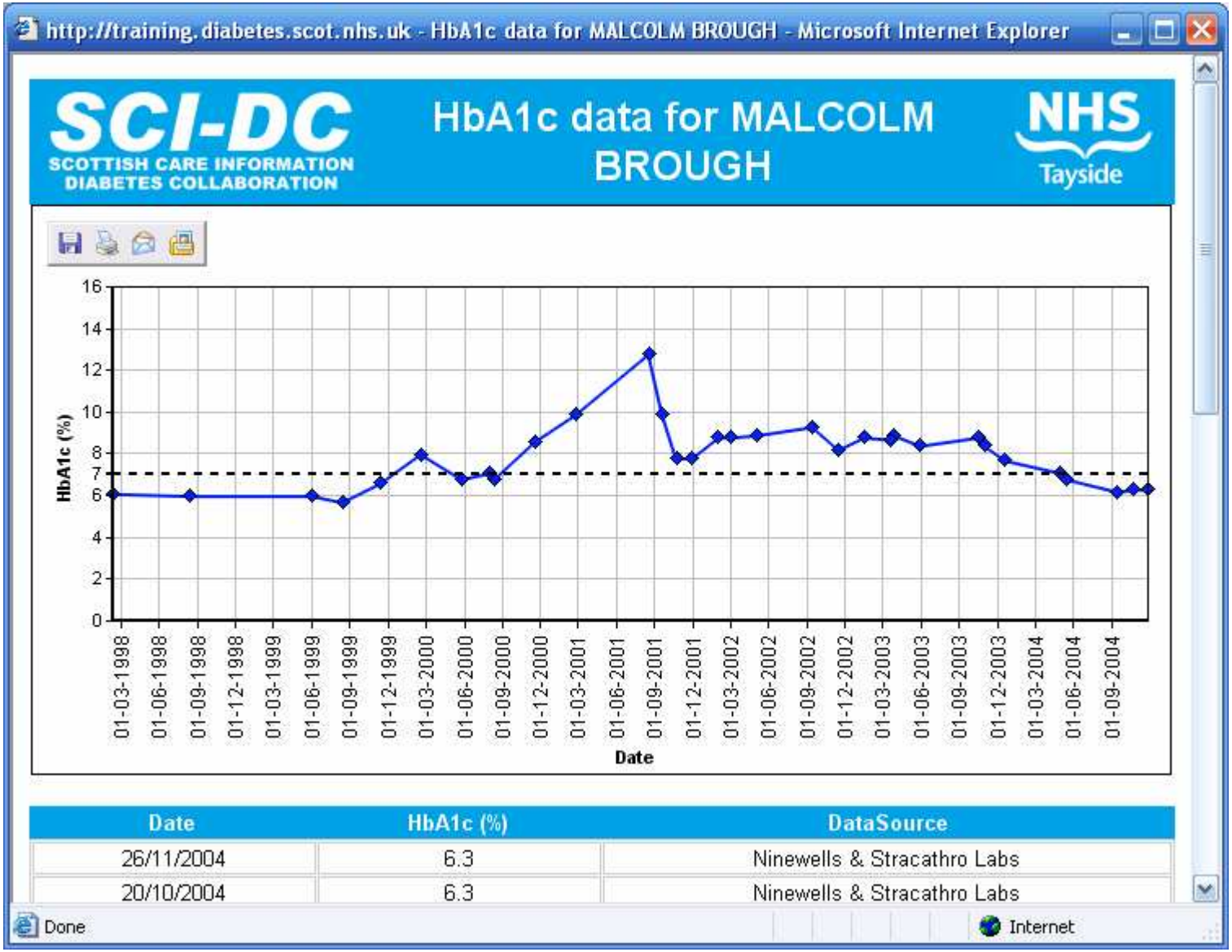
Patient Log

Source: S.Cunningham, Tayside Diabetes Network



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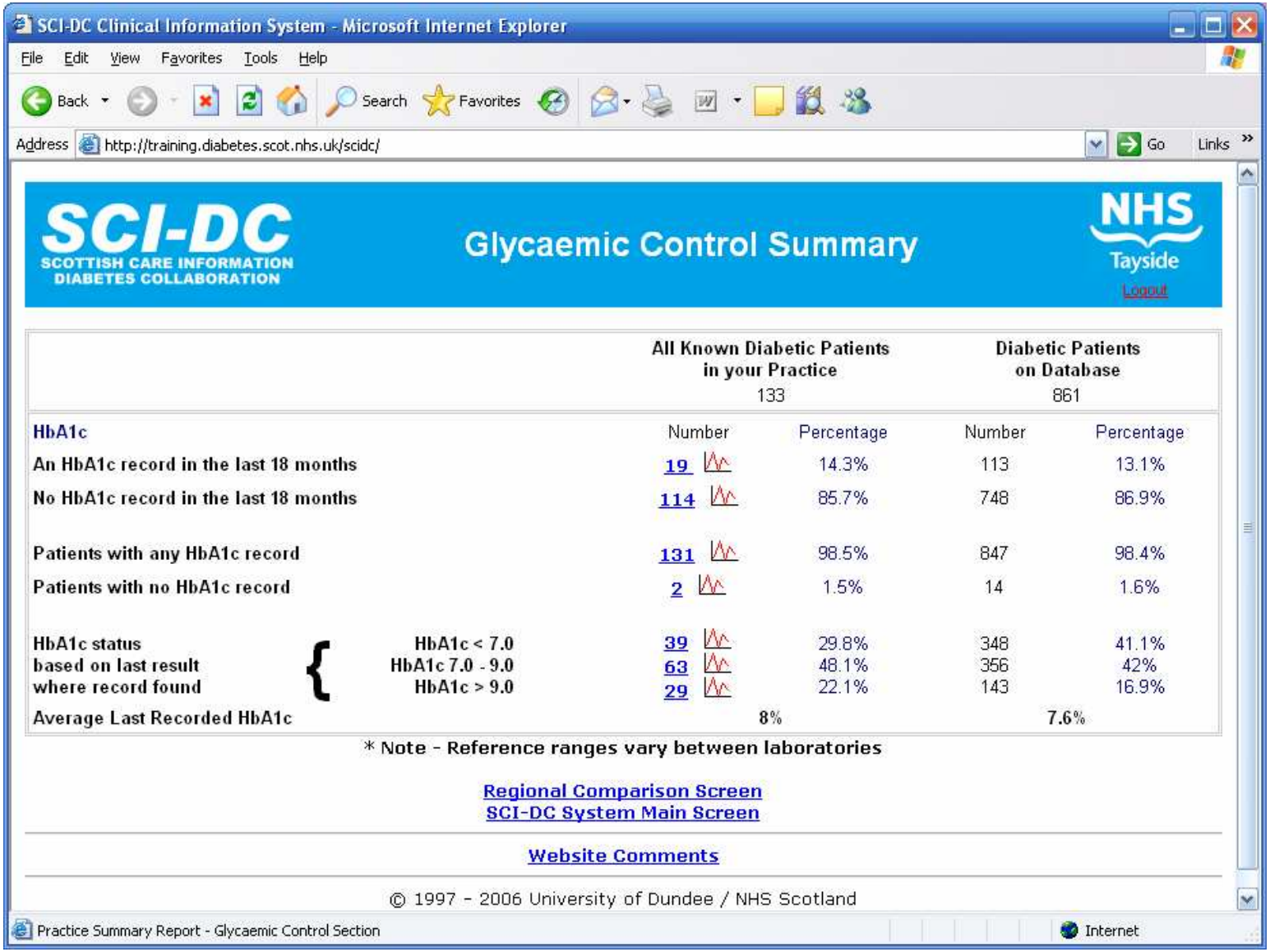
Automated Regional Comparisons

Source: S.Cunningham, Tayside Diabetes Network



		All Known Diabetic Patients in your Practice 133		Diabetic Patients on Database 861	
HbA1c		Number	Percentage	Number	Percentage
An HbA1c record in the last 18 months		19	14.3%	113	13.1%
No HbA1c record in the last 18 months		114	85.7%	748	86.9%
Patients with any HbA1c record		131	98.5%	847	98.4%
Patients with no HbA1c record		2	1.5%	14	1.6%
HbA1c status based on last result where record found	HbA1c < 7.0	39	29.8%	348	41.1%
	HbA1c 7.0 - 9.0	63	48.1%	356	42%
	HbA1c > 9.0	29	22.1%	143	16.9%
Average Last Recorded HbA1c		8%		7.6%	

* Note - Reference ranges vary between laboratories

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http://www.diabetes-healthnet.ac.uk

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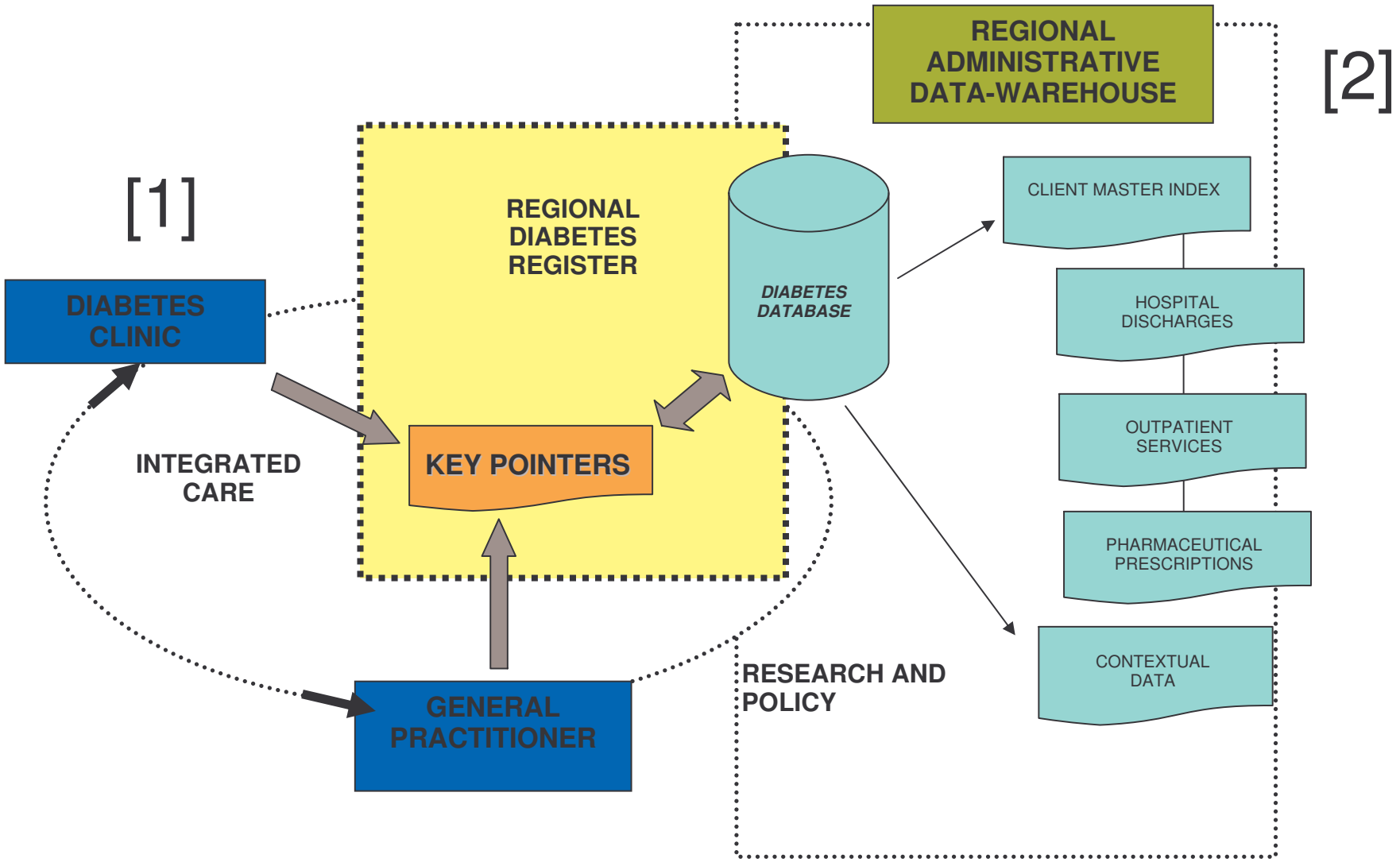
Case Study: Umbria

Source: Massi Benedetti M, Carinci F, Federici MO.
The Umbria diabetes register, *Diabetes Res Clin Pract.* 2006 Dec;74 Suppl 2:S200-4



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Benchmarking analysis

Source: M.Massi Benedetti, Regione Umbria, 2008

[1]

Tabella 1. Analisi preliminare SVE-D 2006 - Raccolta dati RRDM
Confronto tra Centro e Media (Dati Categorici) per DIABETE TIPO 2

HI_HBA	<=8	>8	N.V.	<=8	>8	N.V.
N	XXXX (59.7)	XXXX (23.8)	XXXX (16.5)	11192 (61.7)	4432 (24.4)	2506 (13.8)
Femmine	XXXX (45.8)	XXXX (52.4)	XXXX (48.3)	5153 (46.0)	2287 (51.6)	1206 (48.1)
Insulina	XXXX (30.2)	XXXX (55.8)	XXXX (14.0)	2041 (18.2)	1710 (38.6)	262 (10.5)
Iporali	XXXX (45.2)	XXXX (41.2)	XXXX (5.0)	3886 (34.7)	1427 (32.2)	168 (6.7)
Metformina	XXXX (28.0)	XXXX (34.4)	XXXX (4.5)	3981 (35.6)	1713 (38.7)	202 (8.1)
Eta						
0-35	XXXX (0.6)	XXXX (0.4)	XXXX (1.2)			
35-55	XXXX (13.9)	XXXX (17.6)	XXXX (15.7)			
55-75	XXXX (62.3)	XXXX (61.6)	XXXX (51.5)			
75+	XXXX (22.4)	XXXX (19.9)	XXXX (28.0)			
N.V.	XXXX (0.8)	XXXX (0.5)	XXXX (3.6)			
Durata Diabete						
0-10	XXXX (44.8)	XXXX (38.4)	XXXX (23.9)			
10-20	XXXX (17.8)	XXXX (21.3)	XXXX (11.8)			
20+	XXXX (12.8)	XXXX (18.5)	XXXX (14.5)			
N.V.	XXXX (24.7)	XXXX (21.9)	XXXX (49.8)			
BMI						
0-25	XXXX (13.0)	XXXX (10.4)	XXXX (1.1)			
25-27	XXXX (13.0)	XXXX (9.9)	XXXX (1.5)			
27-30	XXXX (21.5)	XXXX (18.8)	XXXX (1.7)			
30-40	XXXX (24.2)	XXXX (29.4)	XXXX (3.3)			
>40	XXXX (1.9)	XXXX (2.9)	XXXX (0.4)			
N.V.	XXXX (26.4)	XXXX (28.5)	XXXX (92.0)			
Colesterolo LDL						
0-10	XXXX (7.4)	XXXX (7.1)	XXXX (1.0)			
10-20	XXXX (8.3)	XXXX (5.9)	XXXX (0.6)			
20+	XXXX (7.9)	XXXX (8.1)	XXXX (0.9)			
N.V.	XXXX (76.4)	XXXX (78.9)	XXXX (97.5)			

Confronto tra Centro e Media (Dati Continui) per DIABETE TIPO 2

HI_HBA	<=8	>8	N.V.	<=8	>8	N.V.
Colesterolo Totale	203.1 (39.4)	208.1 (43.1)	216.6 (48.2)	206.6 (36.8)	211.5 (39.9)	221.1 (48.2)
N.V.	XXXX (61.5)	XXXX (62.4)	XXXX (95.5)	3219 (28.8)	1394 (31.5)	2087 (83.3)
Colesterolo HDL	51.8 (13.3)	51.6 (13.7)	48.7 (13.7)	52.8 (13.2)	51.8 (13.1)	48.8 (12.5)
N.V.	XXXX (64.9)	XXXX (66.8)	XXXX (96.0)	3693 (33.0)	1654 (37.3)	2223 (88.7)
Creatinina	1.1 (0.5)	1.0 (0.4)	1.2 (0.8)	1.0 (0.5)	1.0 (0.4)	1.1 (0.7)
N.V.	XXXX (74.3)	XXXX (74.1)	XXXX (97.4)	3929 (35.1)	1650 (37.2)	2165 (86.4)
Glicemia	150.7 (30.8)	206.8 (52.0)	186.4 (76.7)	146.6 (30.4)	200.9 (52.1)	179.1 (72.2)
N.V.	XXXX 1 (5.6)	XXXX (7.3)	XXXX (90.7)	535 (4.8)	298 (6.7)	1700 (67.8)
Microalbuminuria	20.7 (40.2)	23.0 (36.8)	12.4 (8.6)	24.0 (39.6)	33.9 (49.7)	23.2 (29.6)
N.V.	XXXX (79.0)	XXXX (82.6)	XXXX (99.3)	8577 (76.6)	3628 (81.9)	2472 (98.6)
Pressione Diastolica	76.8 (10.6)	78. (12.2)	78.4 (16.7)	81.2 (9.1)	81.9 (9.1)	82.4 (9.9)
N.V.	XXXX (79.8)	XXXX (78.9)	XXXX (97.1)	4566 (40.8)	2058 (46.4)	1769 (70.6)
Pressione Sistolica	134.2 (19.0)	136.0 (21.5)	124.5 (17.2)	141.5 (17.2)	142.8 (18.4)	142.8 (19.7)
N.V.	XXXX (79.8)	XXXX (78.9)	XXXX (97.1)	4563 (40.8)	2060 (46.5)	1770 (70.6)
Trigliceridi	159.0 (78.8)	173.4 (92.8)	209.4 (91.7)	152.5 (74.3)	170.8 (90.7)	192.1 (91.8)
N.V.	XXXX (61.9)	XXXX (64.2)	XXXX (96.4)	8433 (75.3)	3556 (80.2)	2438 (97.3)
Numero Visite	5.8 (6.0)	4.8 (5.5)	1.1 (0.6)	5.5 (5.6)	4.8 (5.4)	1.2 (0.6)
N.V.	0 (0.0)	XXXX (0.0)	XXXX (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Giorni di Osservazione	797.3 (696.5)	683.3 (703.9)	33.1 (175.4)	880.7 (827.8)	839.4 (888.6)	68.2 (279.5)
N.V.	XXXX (0.1)	XXXX (0.1)	XXXX (0.0)	6 (0.1)	3 (0.1)	0 (0.0)

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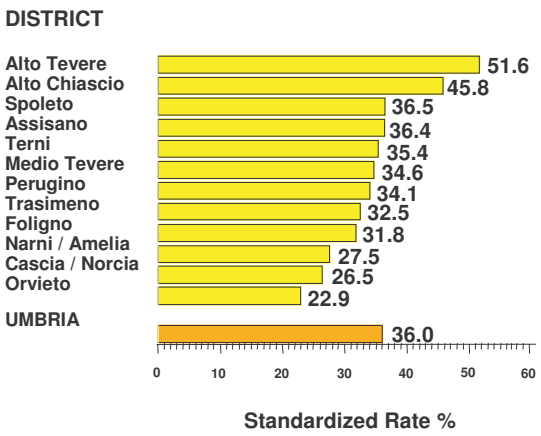
Best Information through Regional Outcomes

Diabetes Indicators for the Regional Evaluation of Outcomes

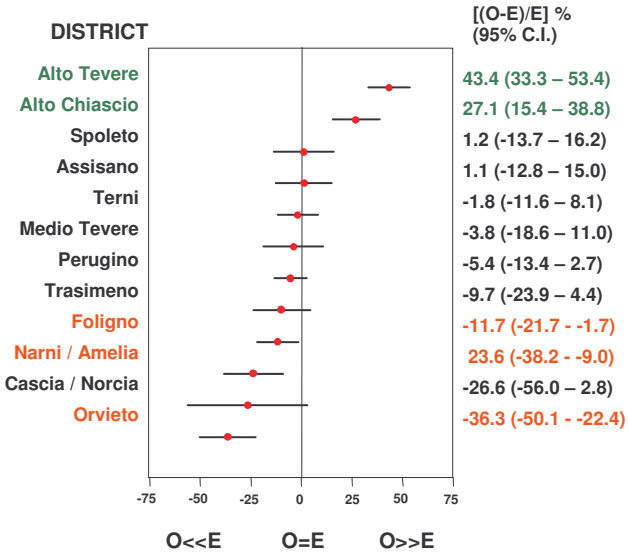
Source: Carinci F, SVE/DVSS Project, University of Perugia 2008

[2]

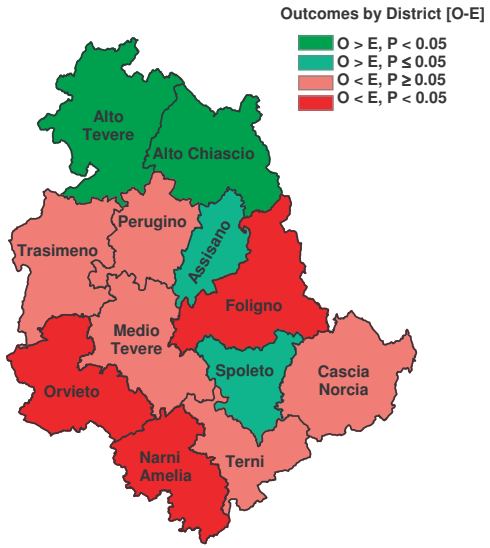
FREQUENCIES



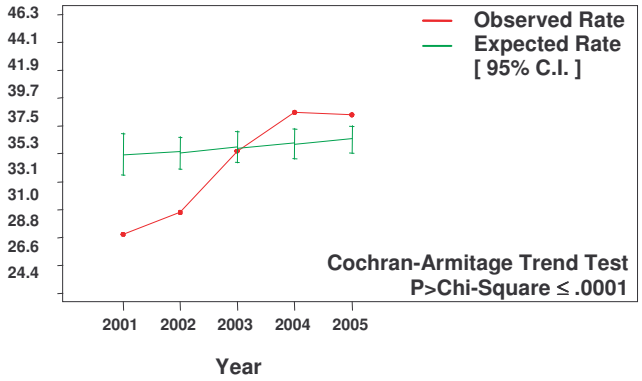
PERCENT DIFFERENCE OBSERVED - EXPECTED



GEOGRAPHICAL VARIATION



TRENDS



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Perugia, 25th May 2009

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The Norwegian Diabetes Registry for Adults

NOKLUS Diabetes

A structured documentation tool for general practices, spesialist practices and hospitals

Magne Rekdal, MD
IT Consultant NDV
Owner Emetra AS
magne@emetra.no

Directorate-General for Health & Consumers

Perugia, 25th May 2009

B.I.R.

Best Information through Regional Outcomes

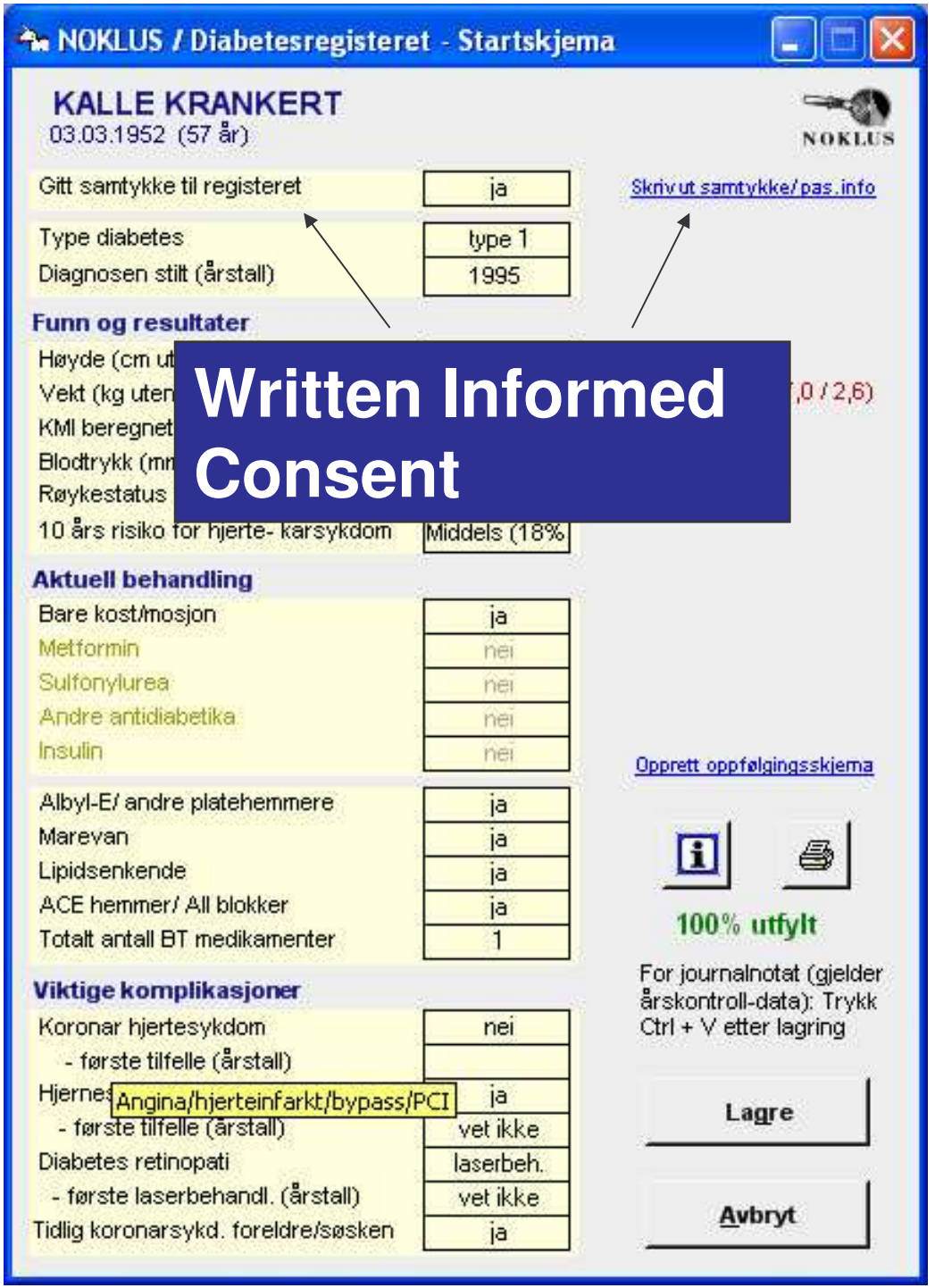
- Simple setup, core dataset in common for practices and hospitals

- A clinical tool

- Cooperation with the diabetes association

- Annual data collection, benchmarking/ feedback

- Privacy



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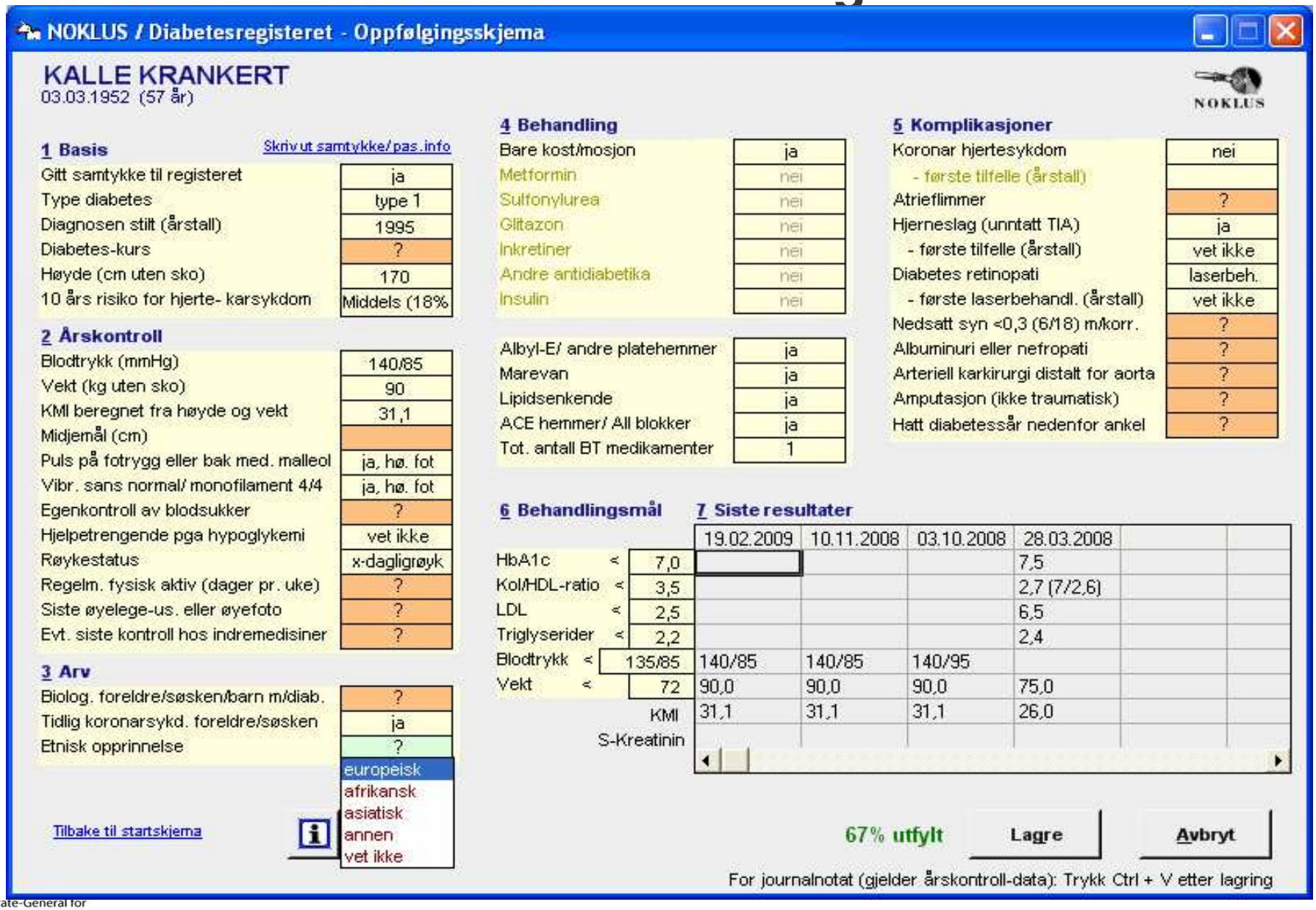
Follow-up visit, old information integrated



B.I.R.

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Scope of a European Diabetes Register

- Link regional experiences
- Learn from practice
- Exchange best practice
- Create common language
- Standardize reports
- Update collaboratively
- Disseminate results

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BIRO Report Template

A "template" is a document or file having a preset format, used as a starting point for a particular application so that the format does not have to be recreated each time it is used

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Indicators and statistical output for each BIRO-user

Governance

Indicator	Planned statistical outputs
1. Demographic characteristics	
1.1 Age (Classes)	Table, histogram
1.2 Gender	Table, histogram
2. Clinical characteristics	
2.1 Diabetes status	
2.1.1 Type of diabetes	Table, histogram
2.1.2 Duration of diabetes	Table, histogram
2.2 Risk factors for diab. complications	
2.2.1 Obesity	
2.2.1.1 Weight	Table, lines
2.2.1.2 BMI	Table, lines

Underlined preferred output

Health care and research

Indicator	Planned statistical outputs
1. Demographic characteristics	
1.1 Age (Classes)	Table, histogram
1.2 Gender	Table, histogram
2. Clinical characteristics	
2.1 Diabetes status	
2.1.1 Type of diabetes	Table, histogram
2.1.2 Duration of diabetes	Table, histogram
2.2 Risk factors for diab. complications	
2.2.1 Obesity	
2.2.1.1 Weight	Table, lines, starplot, boxplot
2.2.1.2 BMI	Table, lines, starplot, boxplot

Different output according to target audience

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Final BIRO Report Indicators

- Demographic Characteristics (N=2)
- Clinical Characteristics (N=18)
- Health System (N=21)
- Population (N=3)
- Risk Adjusted (N=28)
  - Epidemiology (N=2)
  - Process Quality (N=16)
  - Intemediate Outcomes (N=7)
  - Terminal Outcomes (N=3)

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Web Portal Homepage

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Web Portal Data Dictionary

Reference	Name	Parameter	Datatype	Units
BIRO001	PAT_ID	Patient ID	String(12)	
BIRO002	DS_ID	Data Source ID	String(10)	
BIRO003	TYPE_DM	Type Of Diabetes	Enumerated	

Code	Value
1	Type 1
2	Type 2
3	Other Types of Diabetes

BIRO004	SEX	Sex	Enumerated	
BIRO005	DOB	Date of Birth	Date/Time	
BIRO006	DT_DIAG	Date of Diagnosish	Integer	
BIRO007	EPI_DATE	Episode Date	Date/Time	
BIRO008	SMOK_STAT	Smoking Status	Enumerated	
BIRO009	CIGS_DAY	Cigarettes per day	Integer	
BIRO047	ALC_STAT	Alcohol Status	Enumerated	g/week
BIRO010	ALCOHOL	Alcohol Intake	Integer	g/week
BIRO011	WEIGHT	Weight	Real	kg
BIRO012	HEIGHT	Height	Real	m
BIRO013	BMI	Body Mass Index	Real	kg/m2

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Web Portal Reports

Biro Indicators

Best Information through Regional Outcomes

Biro Indicators

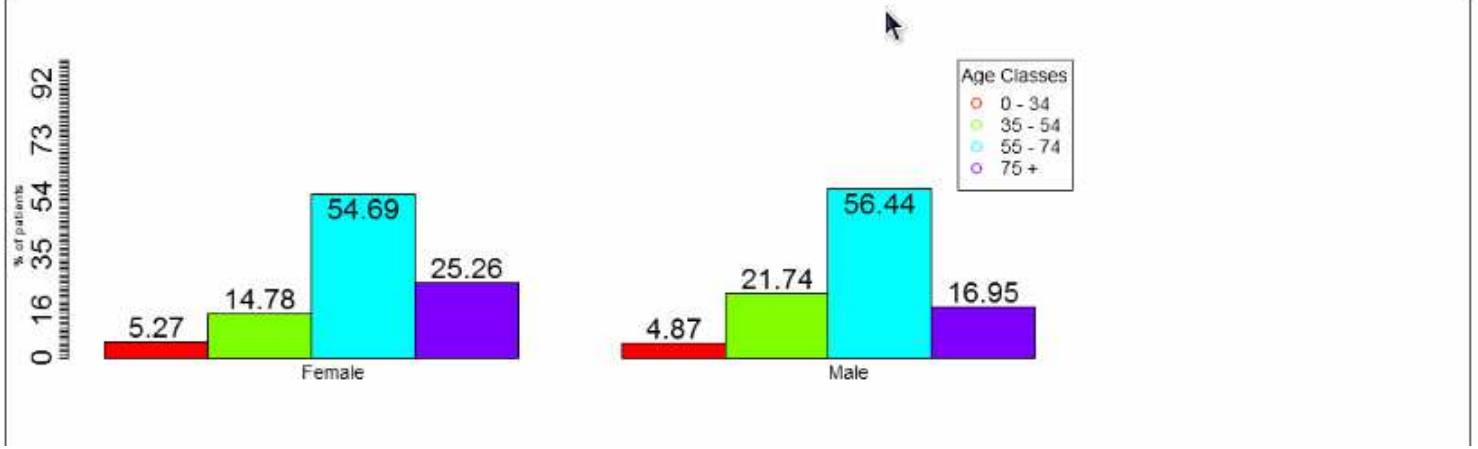
- Home
- Why BIRO
- BIRO model
- Diabetes info
- Diabetes Indicators
  - 1. Demographic characteristics
    - 1.1. Age (Classes)
    - 1.2. Gender
  - 2. Clinical characteristics
  - 3. Health system
  - 4. Population (Area level)
  - 5. Risk adjusted indicators
- Data dictionary
- Work packages
- Project partners
- E-learning
- How to participate

Home » Diabetes Indicators » 1. Demographic characteristics » 1.1. Age (Classes)

1.1. Age (Classes)

Indicator Definition

Age Classes	Female	Male	
0 - 34	775 (49.81 %)	781 (50.19 %)	1556 (5.06 %)
35 - 54	2175 (38.40 %)	3489 (61.60 %)	5664 (18.41 %)
55 - 74	8046 (47.04 %)	9058 (52.96 %)	17104 (55.6 %)
75 +	3716 (57.74 %)	2720 (42.26 %)	6436 (20.92 %)
	14712 (47.83 %)	16048 (52.17 %)	30760



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The future is ahead……

Thank you !