

# 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*

# Questions for Policy and Practice

You cannot manage what you cannot measure

Can you improve what you cannot manage?

# 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]

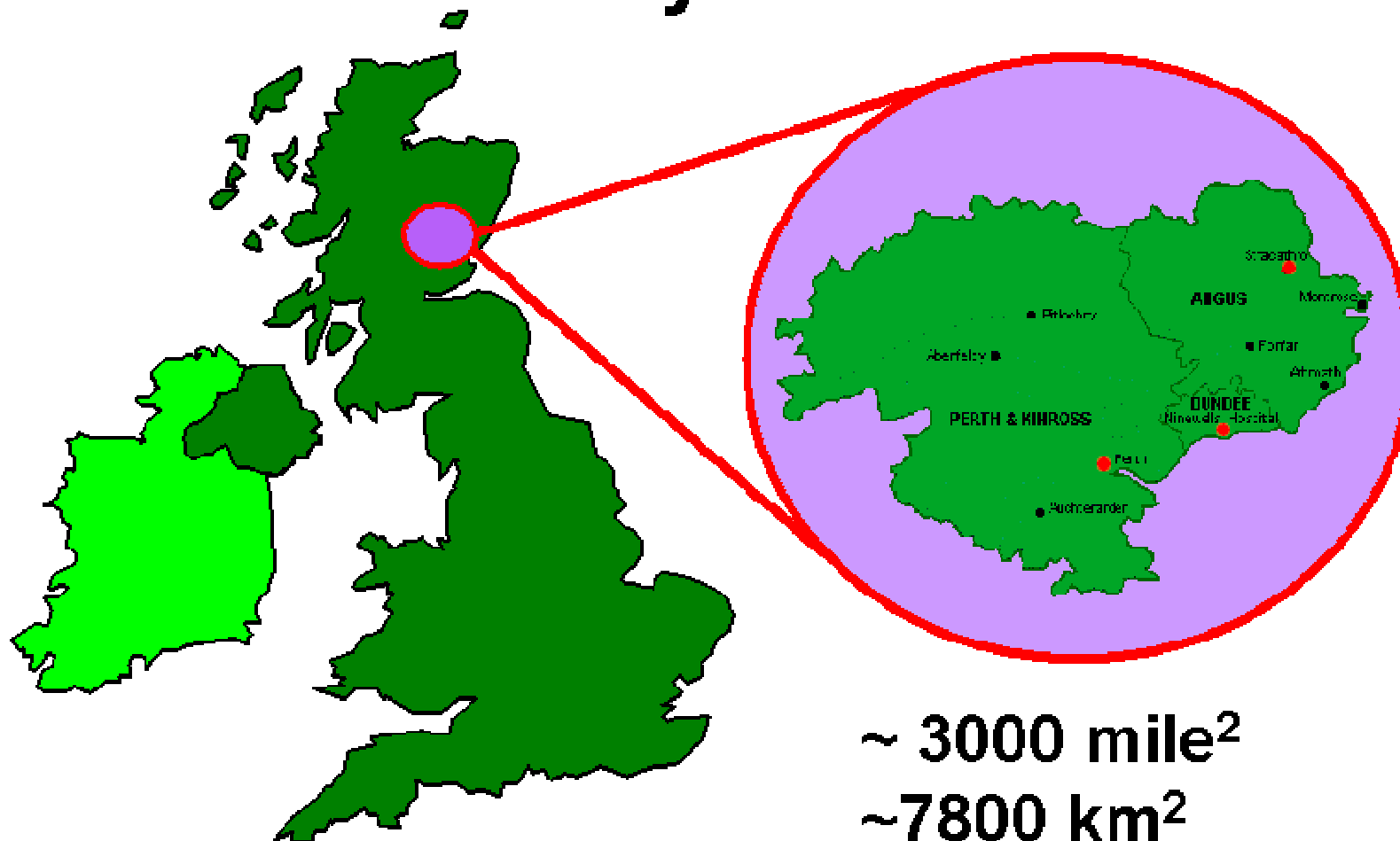
## How should we treat diabetes?

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

# Case Study: Scotland

Source: R.McAlpine, Tayside Diabetes Network

## Tayside



~ 3000 mile<sup>2</sup>

~7800 km<sup>2</sup>

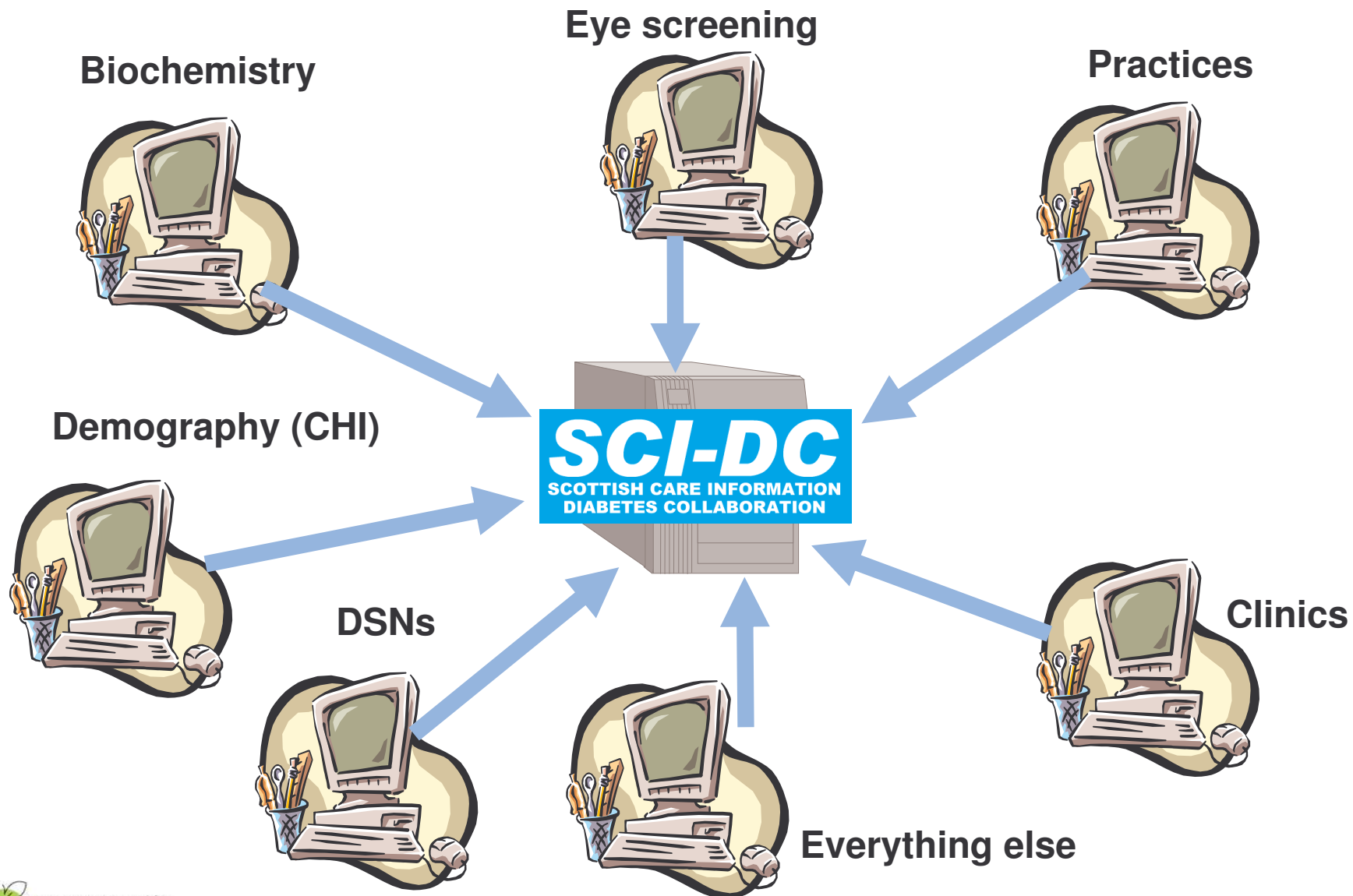
# Progressive transition

Source: R.McAlpine, Tayside Diabetes Network



## Complete data flow

Source: R.McAlpine, Tayside Diabetes Network

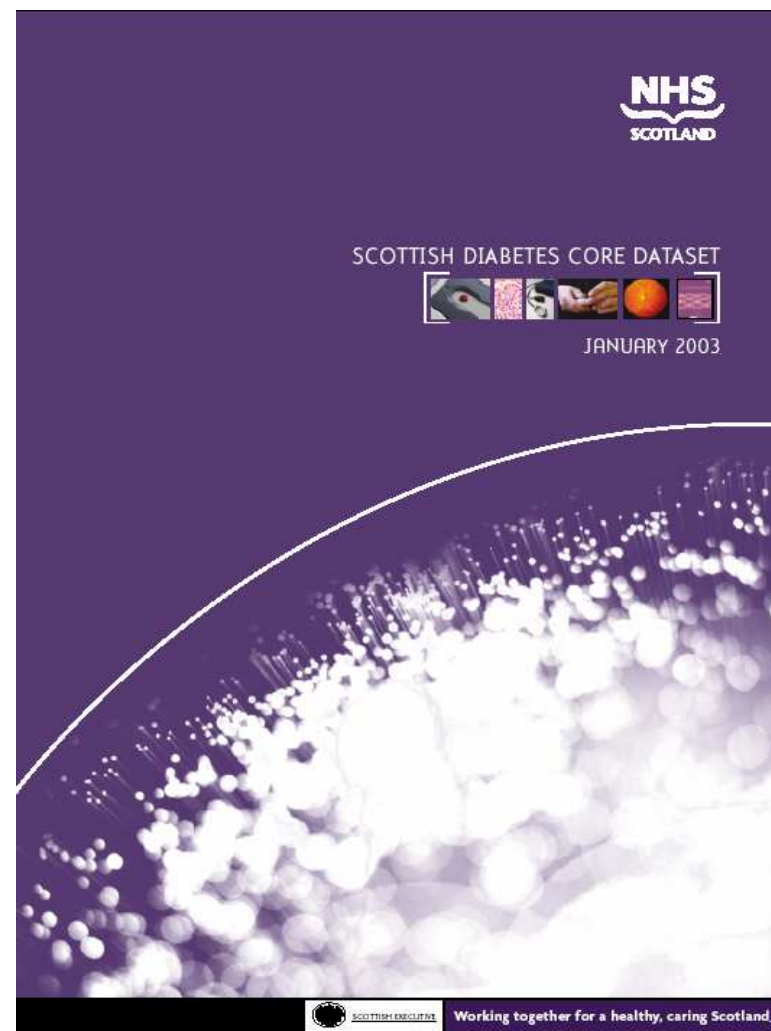


# Case Study: Scotland

Source: S.Cunningham, Tayside Diabetes Network

## COMMON LANGUAGE

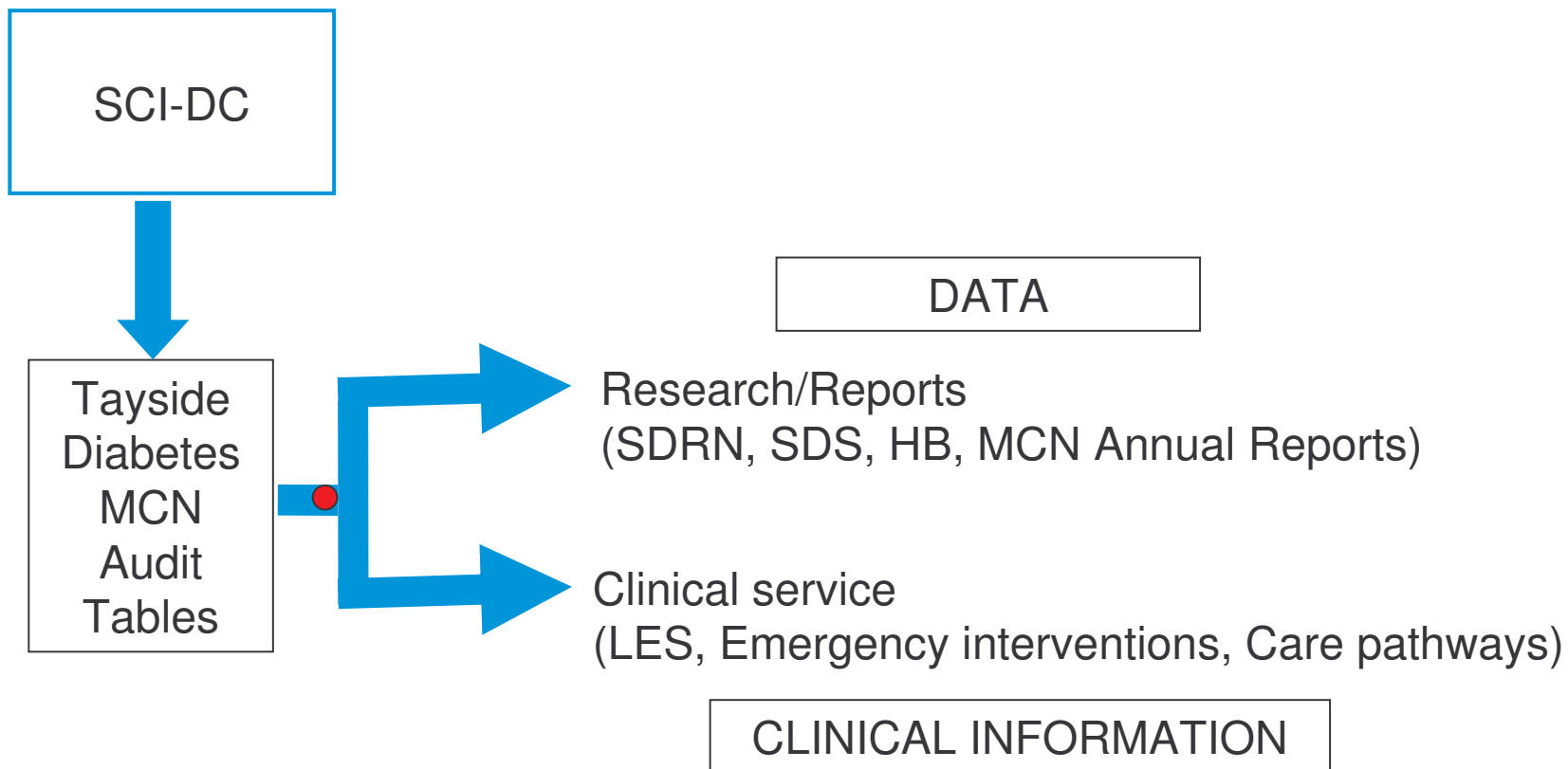
- Standardised dictionary of terms
- Clear and unambiguous clinical definitions





# Information Split

Source: R.McAlpine, Tayside Diabetes Network



# Local Enhanced Service

Source: R.McAlpine, Tayside Diabetes Network

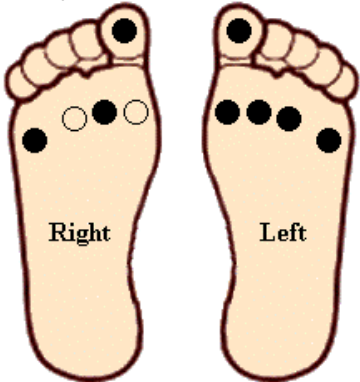
DC Clinical Information System - Microsoft Internet Explorer

https://ecc.diabetes.scot.nhs.uk/scidc/

Vascular Assessment : [Handbook](#) [Leaflet](#)

	Right	Left
Amputation :	None / /	None / /
Dorsalis Pedis :	<input type="radio"/> Present <input type="radio"/> Impaired <input checked="" type="radio"/> Absent	<input type="radio"/> Present <input type="radio"/> Impaired <input checked="" type="radio"/> Absent
Posterior Tibial :	<input type="radio"/> Present <input type="radio"/> Impaired <input checked="" type="radio"/> Absent	<input type="radio"/> Present <input type="radio"/> Impaired <input checked="" type="radio"/> Absent
Intermittent Claudication :	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No
Previous Vascular Surgery :	<input type="radio"/> Yes <input type="radio"/> No	<input type="radio"/> Yes <input type="radio"/> No

**Neurological Assessment**  
10 Gram Monofilament Sites  
Response = ● No Response = ○



Right                  Left

Feeling in only 8/10 sites or less?  
Significant Neuropathy = **Yes**

**Neurological Symptoms Present**  
(i.e. pain, paraesthesia, burning)       Yes       No

**Other Risk Factors**

Impaired Sight :  Yes  No

Callus :  Yes  No

Significant Foot Deformity :  Yes  No

Active Ulceration :  Yes  No

Previous Ulceration :  Yes  No

Physical Disability :  Yes  No

**Risk Category**  
**High**

Foot Health Education Given :  Yes  No

**Referral Status**

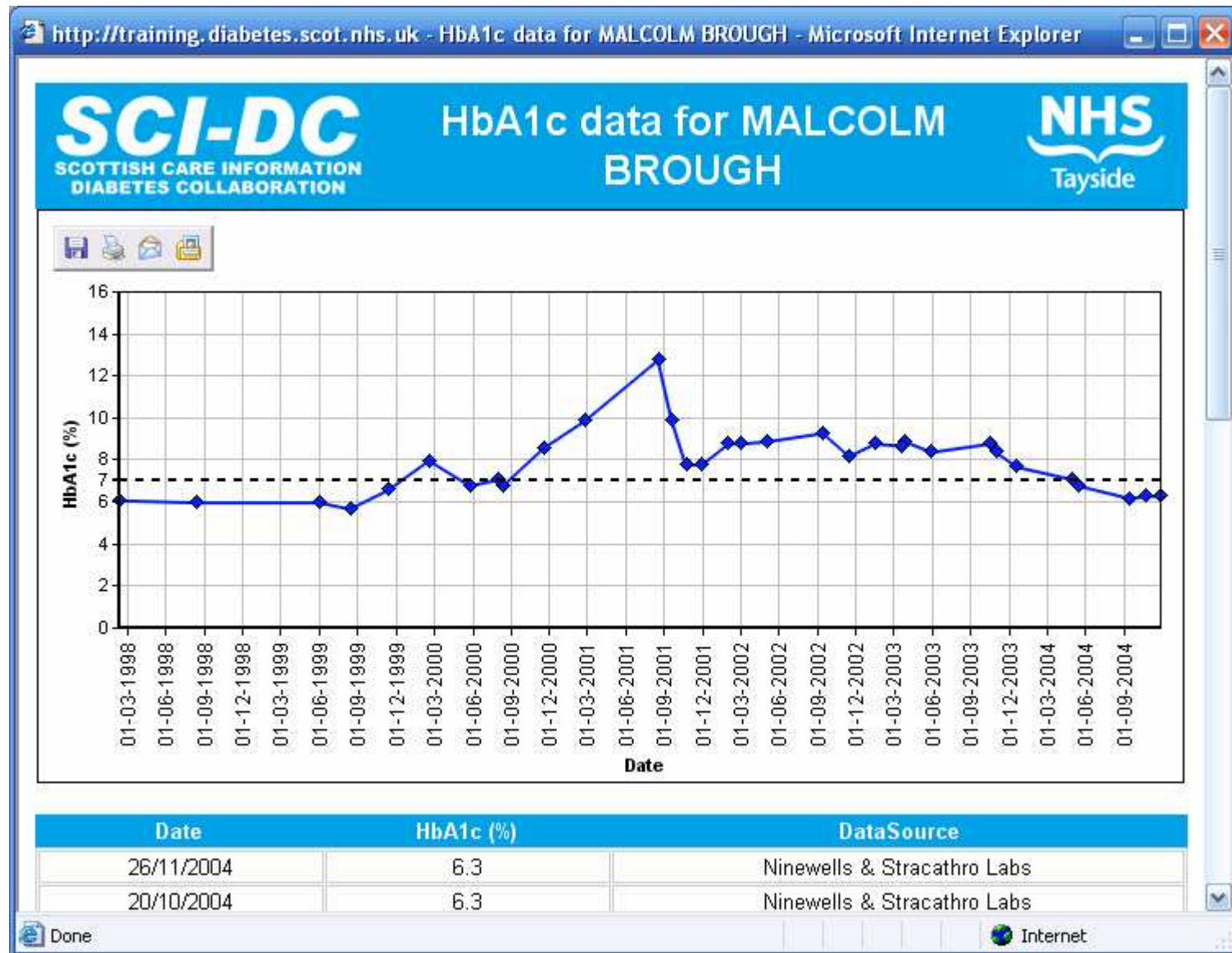
Refer to Podiatry Dept. :  Yes  No

[Blank Referral Form](#)    [Pre-Completed Referral Form](#)

Refer To Other Dept. :  Yes  No  
(specify)

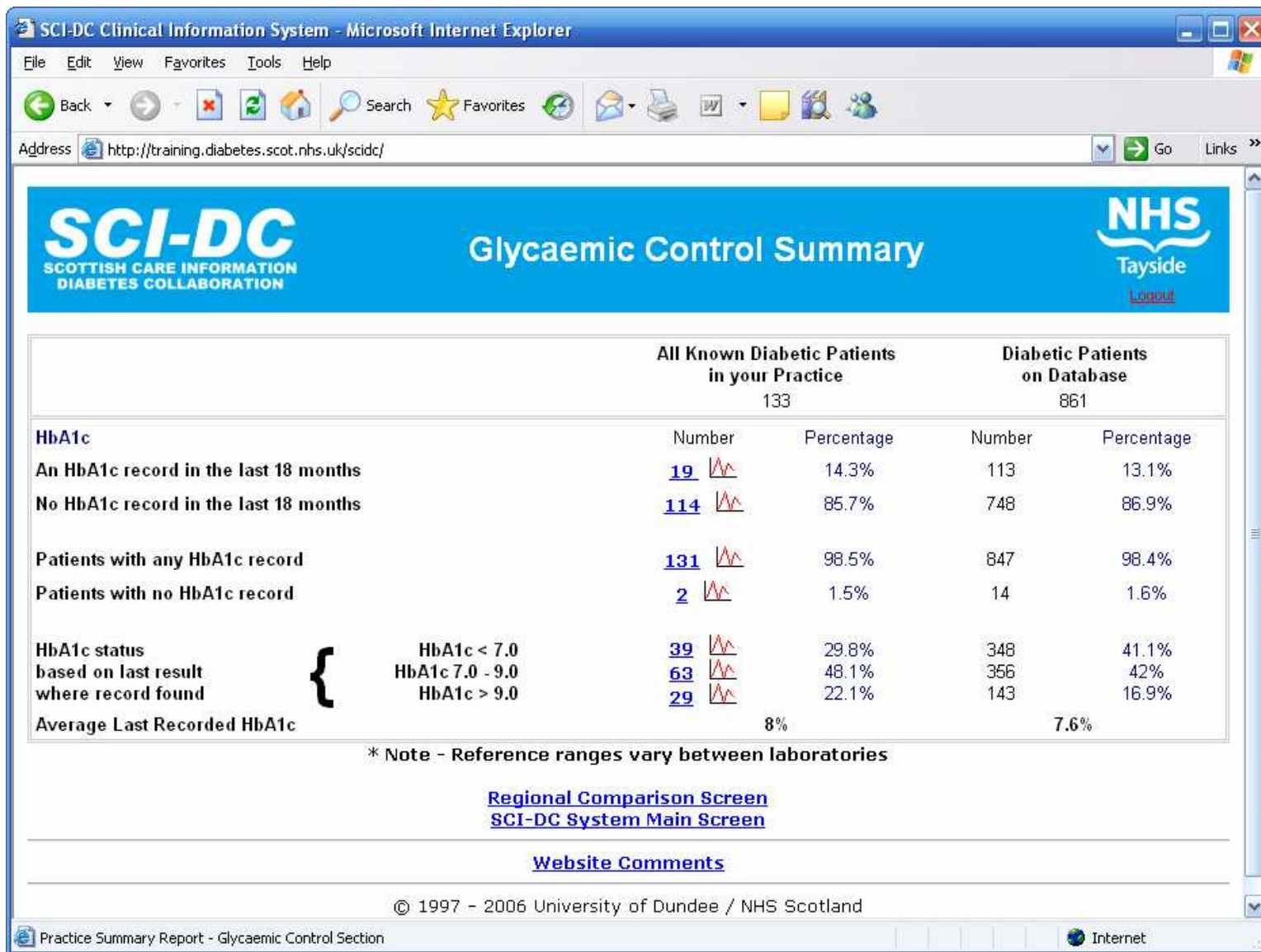
# Patient Log

Source: S.Cunningham, Tayside Diabetes Network



# Automated Regional Comparisons

Source: S.Cunningham, Tayside Diabetes Network





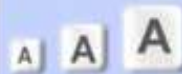
## NHS Tayside Diabetes MCN



[Home page](#)

[Login](#)

Change text size



### Main Menu

- [Home page](#)
- [Meet the Team](#)
- [Handbook](#)
- [Specialist Clinics](#)
- [Patient Information](#)
- [Children Services](#)
- [Professional Education](#)
- [Eye Screening](#)
- [Footsteps](#)
- [MCN](#)
- [Latest News](#)
- [Research](#)
- [Links](#)
- [Search this Site](#)
- [Admin home](#)



### Latest News...

**May 2009**  
[Read more...](#)

### Welcome to the website of NHS Tayside's Diabetes Managed Clinical Network (MCN).

The MCN is a coordinated network of professionals involved in providing diabetes care across the region. Within this network patients and professionals work together to continually develop and improve this care. This website provides local information about diabetes and diabetes care for both healthcare professionals and patients.

We hope you find the site useful and would appreciate feedback on any aspect of the site or the information provided. Please send your comments to: [Elaine Wilson](#)

#### Meet the Team

Team members of the Tayside Diabetes Clinical Network.

#### Specialist Clinics

Specialist Diabetes Clinics across Tayside

#### Children's Services

Services and guidelines for children

#### Eye Screening

Details of the Retinopathy screening programme

#### Latest News

Latest Tayside Diabetes news and events.

#### Links

Diabetes Web Links

#### Search this Website

Powered by @Google Custom Search

#### Handbook

Guidelines for diabetes care.

#### Patient Information

Information for patients including patient leaflets, events, groups.

#### Professional Education

Information about educational opportunities, conferences, locality forums.

#### Footsteps

Podiatry Self Management Education Programme.

#### Research

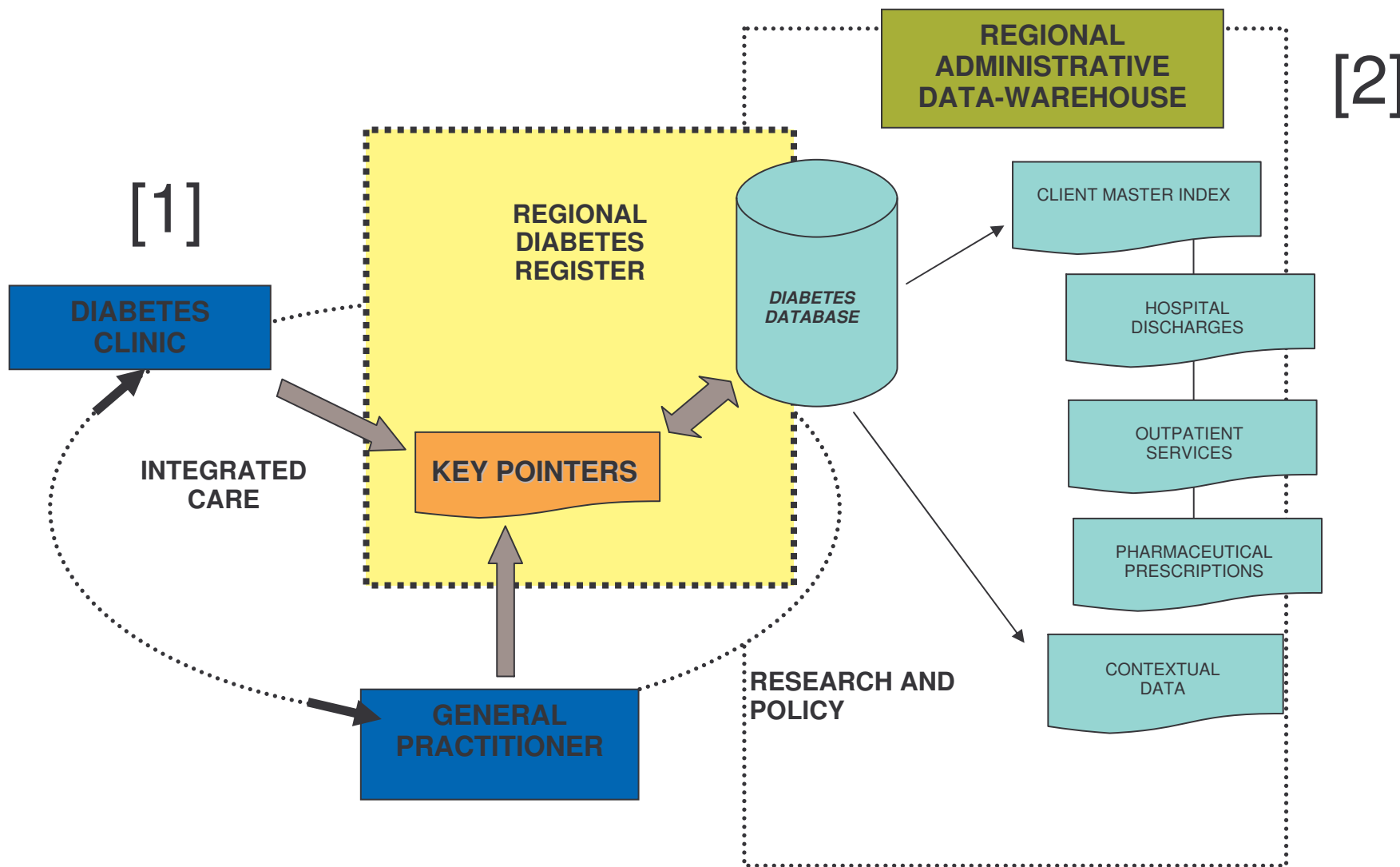
Diabetes research in Tayside.

#### MCN

Managed Clinical Network Documents including strategy, annual reports.

# 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



# 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.
<b>N</b>	XXXX (59.7)	XXXX (23.8)	XXXX (16.5)	11192 (61.7)	4432 (24.4)	2508 (13.8)
<b>Femmine</b>	XXXX (45.8)	XXXX (52.4)	XXXX (48.3)	5153 (46.0)	2287 (51.6)	1208 (48.1)
<b>Insulina</b>	XXXX (30.2)	XXXX (55.8)	XXXX (14.0)	2041 (18.2)	1710 (38.6)	262 (10.5)
<b>Iporali</b>	XXXX (45.2)	XXXX (41.2)	XXXX (5.0)	3988 (34.7)	1427 (32.2)	188 (6.7)
<b>Metformina</b>	XXXX (28.0)	XXXX (34.4)	XXXX (4.5)	3981 (35.6)	1713 (38.7)	202 (8.1)
<b>Eta</b>						

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

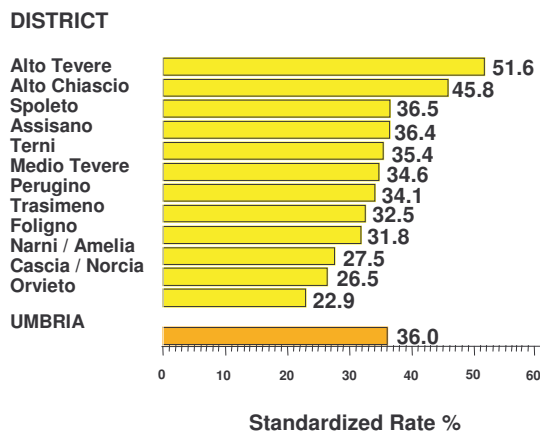
HI_HBA	<=8	>8	N.V.	<=8	>8	N.V.
<b>Cholesterolo Totale</b>	203.1 (39.4)	208.1 (43.1)	216.6 (48.2)	206.6 (36.6)	211.5 (39.9)	221.1 (48.2)
<b>N.V.</b>	XXXX (61.5)	XXXX (62.4)	XXXX (95.5)	3219 (26.6)	1394 (31.5)	2087 (83.3)
<b>Cholesterolo HDL</b>	51.8 (13.3)	51.6 (13.7)	48.7 (13.7)	52.8 (13.2)	51.8 (13.1)	48.8 (12.5)
<b>N.V.</b>	XXXX (64.9)	XXXX (66.8)	XXXX (96.0)	3893 (33.0)	1654 (37.3)	2223 (88.7)
<b>Creatinina</b>	1.1 (0.5)	1.0 (0.4)	1.2 (0.8)	1.0 (0.5)	1.0 (0.4)	1.1 (0.7)
<b>N.V.</b>	XXXX (74.3)	XXXX (74.1)	XXXX (97.4)	3929 (35.1)	1650 (37.2)	2185 (86.4)
<b>Glicemia</b>	150.7 (30.8)	208.8 (52.0)	186.4 (76.7)	146.6 (30.4)	200.9 (52.1)	179.1 (72.2)
<b>N.V.</b>	XXXX 1 (5.6)	XXXX (7.3)	XXXX (90.7)	535 (4.8)	298 (6.7)	1700 (67.8)
<b>Microalbuminuria</b>	20.7 (40.2)	23.0 (36.8)	12.4 (8.6)	24.0 (39.6)	33.9 (49.7)	23.2 (29.6)
<b>N.V.</b>	XXXX (79.0)	XXXX (82.6)	XXXX (99.3)	8577 (76.6)	3628 (81.9)	2472 (98.6)
<b>Pressione Diastolica</b>	76.8 (10.8)	78. (12.2)	78.4 (16.7)	81.2 (8.1)	81.8 (9.1)	82.4 (9.9)
<b>N.V.</b>	XXXX (79.8)	XXXX (78.9)	XXXX (97.1)	4566 (40.8)	2058 (46.4)	1789 (70.6)
<b>Pressione Sistolica</b>	134.2 (19.0)	138.0 (21.5)	124.5 (17.2)	141.5 (17.2)	142.8 (18.4)	142.8 (19.7)
<b>N.V.</b>	XXXX (79.8)	XXXX (78.9)	XXXX (97.1)	4563 (40.8)	2060 (46.5)	1770 (70.6)
<b>Trigliceridi</b>	159.0 (78.8)	173.4 (92.8)	209.4 (91.7)	152.5 (74.3)	170.8 (90.7)	192.1 (91.8)
<b>N.V.</b>	XXXX (61.9)	XXXX (64.2)	XXXX (96.4)	8433 (75.3)	3556 (80.2)	2438 (97.3)
<b>Numero Visite</b>	5.8 (6.0)	4.8 (5.5)	1.1 (0.6)	5.5 (5.6)	4.8 (5.4)	1.2 (0.6)
<b>N.V.</b>	0 (0.0)	XXXX (0.0)	XXXX (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
<b>Giorni di Osservazione</b>	797.3 (696.5)	683.3 (703.9)	33.1 (175.4)	890.7 (627.6)	839.4 (688.6)	68.2 (279.5)
<b>N.V.</b>	XXXX (0.1)	XXXX (0.1)	XXXX (0.0)	6 (0.1)	3 (0.1)	0 (0.0)

# Diabetes Indicators for the Regional Evaluation of Outcomes

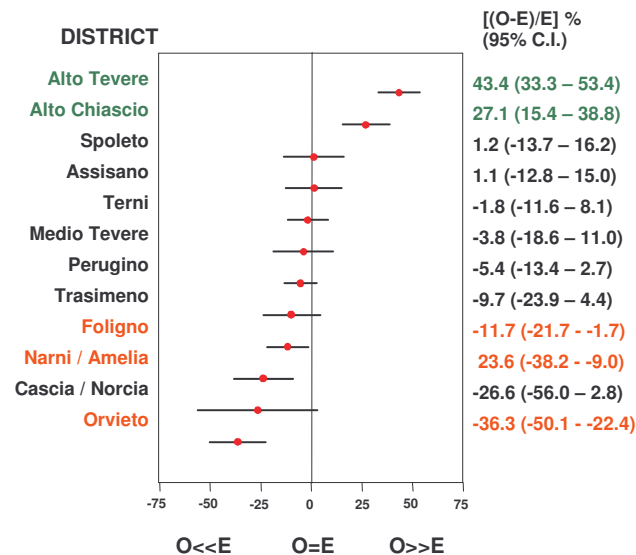
Source: Carinci F, SVE/DVSS Project, University of Perugia 2008

[2]

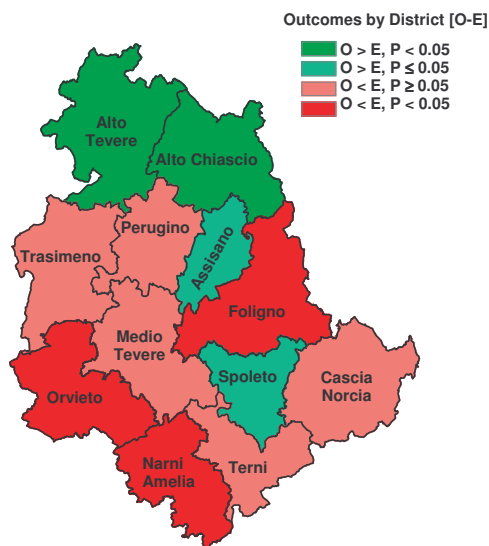
## FREQUENCIES



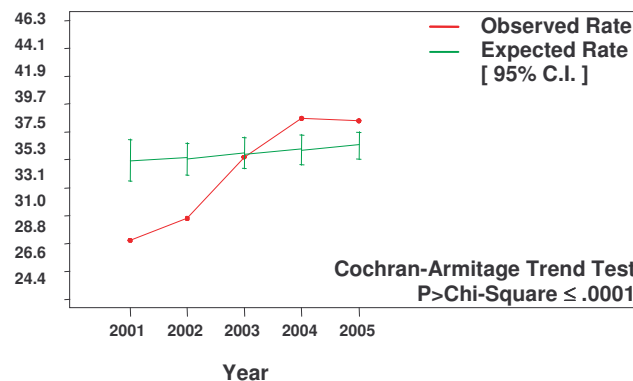
## PERCENT DIFFERENCE OBSERVED - EXPECTED



## GEOGRAPHICAL VARIATION



## TRENDS





# The Norwegian Diabetes Registry for Adults

## NOKLUS Diabetes

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

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

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

- A clinical tool

- Cooperation  
with the  
diabetes  
association

- Annual data  
collection,  
benchmarking/  
feedback

- Privacy

NOKLUS / Diabetesregisteret - Startskjema

**KALLE KRANKERT**  
03.03.1952 (57 år)

Gitt samtykke til registeret  [Skriv ut samtykke/pas.info](#)  
 Type diabetes   
 Diagnosen stilt (årstall)

**Funn og resultater**

Høyde (cm ut)  (0 / 2,6)  
 Vekt (kg uten)   
 KMI beregnet   
 Blodtrykk (mm)   
 Røykestatus   
 10 års risiko for hjerte- karsykdom

**Aktuell behandling**

Bare kost/mosjon   
 Metformin   
 Sulfonylurea   
 Andre antidiabetika   
 Insulin

Albyl-E/ andre platehemmere   
 Marevan   
 Lipidsenkende   
 ACE hemmer/ All blokker   
 Totalt antall BT medikamenter

**Viktige komplikasjoner**

Koronar hjertesykdom   
 - første tilfelle (årstall)

Hjernes    
 - første tilfelle (årstall)

Diabetes retinopati   
 - første laserbehandl. (årstall)

Tidlig koronarsykdom foreldre/søsken

[Opprett oppfølgingsskjema](#)

**100% utfyllt**

For journalnotat (gjelder årskontroll-data): Trykk Ctrl + V etter lagring

# Follow-up visit, old information integrated

**NOKLUS / Diabetesregisteret - Oppfølgingskjema**

**KALLE KRANKERT**  
03.03.1952 (57 år)

**1 Basis** [Skriv ut samtykke/pas.info](#)

Gitt samtykke til registeret	ja
Type diabetes	type 1
Diagnosen stilt (årstall)	1995
Diabetes-kurs	?
Høyde (cm uten sko)	170
10 års risiko for hjerte- karsykdom	Middels (18%)

**2 Årskontroll**

Blodtrykk (mmHg)	140/85
Vekt (kg uten sko)	90
KMI beregnet fra høyde og vekt	31,1
Midjemål (cm)	
Puls på fotrygg eller bak med. malleol	ja, hø. fot
Vibr. sans normal/ monofilament 4/4	ja, hø. fot
Egenkontroll av blodsukker	?
Hjelpetrengende pga hypoglykemi	vet ikke
Røykestatus	x-dagligrøyk
Regelm. fysisk aktiv (dager pr. uke)	?
Siste øyelege-us. eller øyefoto	?
Evt. siste kontroll hos indremedisiner	?

**3 Arv**

Biolog. foreldre/søsken/barn m/diab.	?
Tidlig koronarsykd. foreldre/søsken	ja
Etnisk opprinnelse	?

europeisk  
 afrikansk  
 asiatisk  
 annen  
 vet ikke

**4 Behandling**

Bare kost/mosjon	ja
Metformin	nei
Sulfonylurea	nei
Glitazon	nei
Inkretiner	nei
Andre antidiabetika	nei
Insulin	nei

Albyl-E/ andre platehemmer	ja
Marevan	ja
Lipidsenkende	ja
ACE hemmer/ All blokker	ja
Tot. antall BT medikamenter	1

**5 Komplikasjoner**

Koronar hjertesykdom	nei
- første tilfelle (årstall)	
Atrieflimmer	?
Hjerneslag (unntatt TIA)	ja
- første tilfelle (årstall)	vet ikke
Diabetes retinopati	laserbeh.
- første laserbehandl. (årstall)	vet ikke
Nedsatt syn <0,3 (6/18) m/korr.	?
Albuminuri eller nefropati	?
Arteriell karkirurgi distalt for aorta	?
Amputasjon (ikke traumatisk)	?
Hatt diabetesår nedenfor ankel	?

**6 Behandlingsmål**      **7 Siste resultater**

	19.02.2009	10.11.2008	03.10.2008	28.03.2008
HbA1c <	7,0			7,5
Kol/HDL-ratio <	3,5			2,7 (7/2,6)
LDL <	2,5			6,5
Triglyserider <	2,2			2,4
Blodtrykk <	135/85	140/85	140/85	140/95
Vekt <	72	90,0	90,0	90,0
KMI	31,1	31,1	31,1	26,0
S-Kreatinin				

[Tilbake til startskjema](#)

**67% utfyllt**      **Lagre**      **Avbryt**

For journalnotat (gjelder årskontroll-data): Trykk Ctrl + V etter lagring



Best Information through Regional Outcomes

# Scope of a European Diabetes Register

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

# 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*

# Indicators and statistical output for each BIRO-user

## Governance

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

Underlined  
preferred  
output

Different  
output  
according  
to target  
audience

## Health care and research

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

# 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)
  - Intermediate Outcomes (N=7)
  - Terminal Outcomes (N=3)



Best Information through Regional Outcomes

# Web Portal Homepage



- o Home
- o Why BIRO
- o BIRO model
- o Diabetes info
- Diabetes Indicators
- o Data dictionary
- Work packages
- o Project partners
- o E-learning
- o How to participate

User login

Username: \*

Password: \*

## Content

### BIRO - Best Information through Regional Outcomes

We live in an information age, but good information is still scarce and hard to find.

Chronic conditions in general and diabetes in particular represent a challenge for good health in Europe that is already significant, and which we can expect to become greater in the years to come.

Action must be taken to significantly reduce this burden.

Good indicators to benchmark the problems we face and the steps being taken may represent a powerful mechanism to help bring about improvements and support the identification, dissemination and application of best practice.

The BIRO web portal provides access to the results produced by a sustained effort across countries, organisational and professional boundaries, involving citizens and the wider community through the support of the European Commission.

Nick Fahy

Head of the Health Information Unit

Health and Consumers Directorate-General European Commission







- Biro Indicators**
- o Home
  - o Why BIRO
  - o BIRO model
  - o Diabetes info
  - Diabetes Indicators
  - o Data dictionary
  - Work packages
  - o Project partners
  - o E-learning
  - o How to participate

**User login**

Username: \*

Password: \*

o [Create new account](#)

[Home](#) » [Datadictionary](#) » [Datadictionary](#)

## Datadictionary

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 Diagnosis	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



## Biro Indicators

Best Information through Regional Outcomes

### Biro Indicators

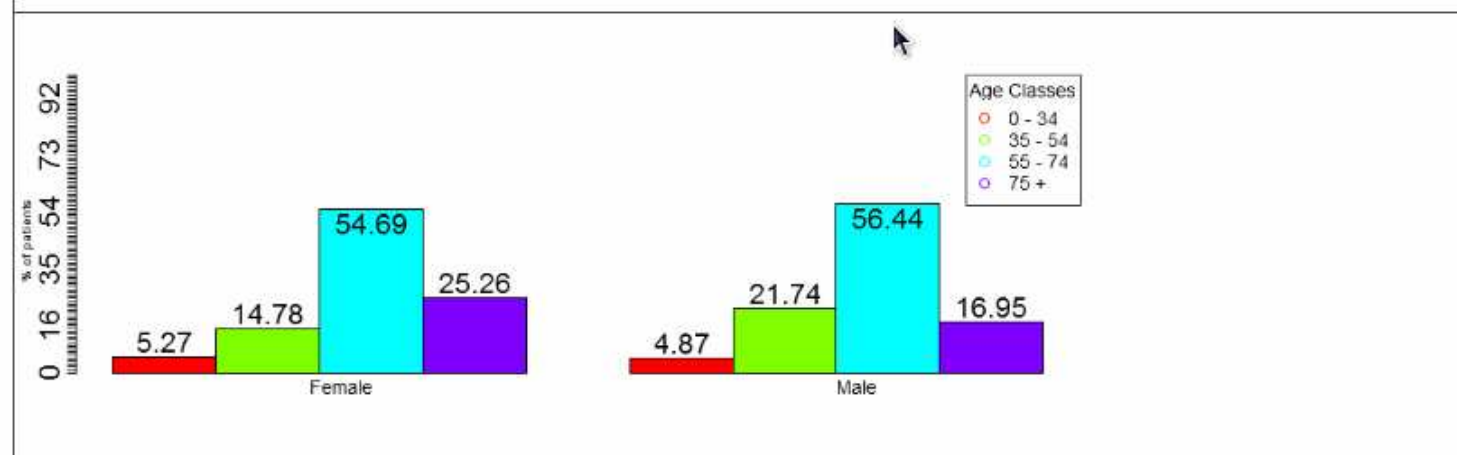
- o Home
- o Why BIRO
- o BIRO model
- o Diabetes info
- o Diabetes Indicators
  - o 1. Demographic characteristics
    - o 1.1. Age (Classes)
    - o 1.2. Gender
  - o 2. Clinical characteristics
  - o 3. Health system
  - o 4. Population (Area level)
  - o 5. Risk adjusted indicators
- o Data dictionary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





Best Information through Regional Outcomes

**The future is ahead.....**

Thank you !