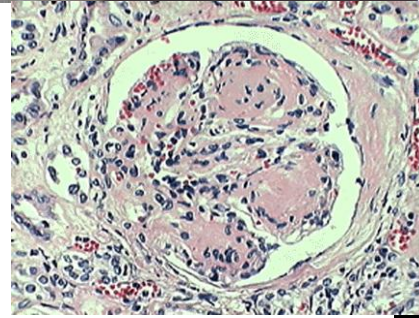
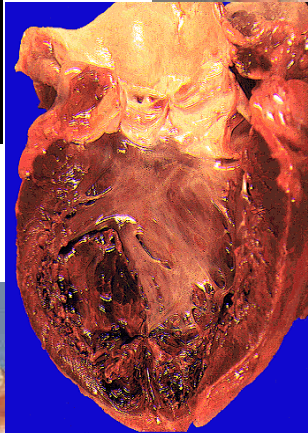
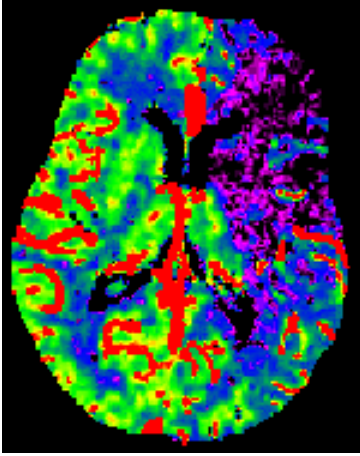


The role of diabetes registries to monitor the treatment and complications of diabetes

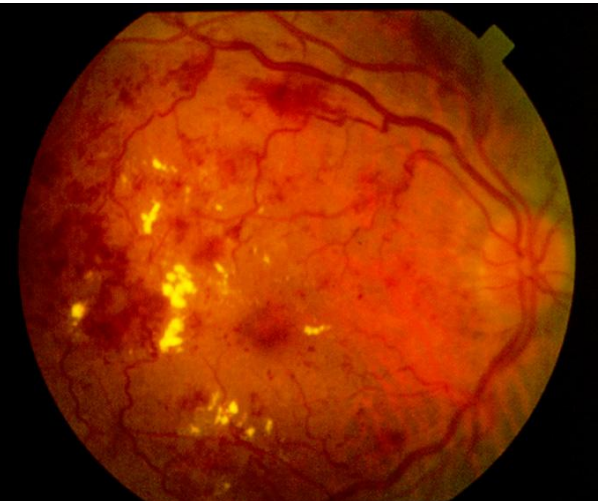
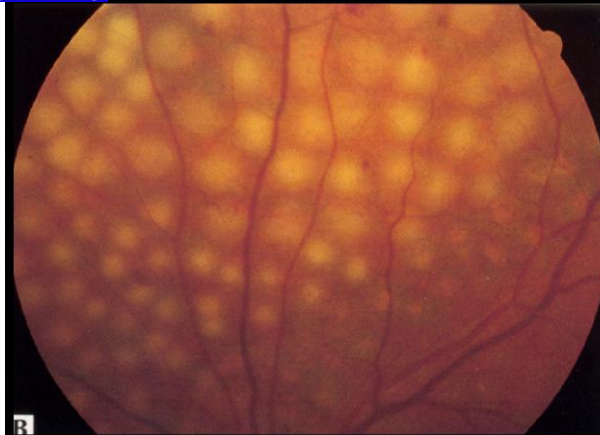
John McKnight

The role of diabetes registries
to improve the care and
prevent, detect and manage
the complications of diabetes

Complexity of Care



© Cornell University Medical College



The 'players'

- **A and C staff**
- **Carers**
- **Consultants**
- **Civil servants**
- **Diabetes nurse specialists**
- **Dietitians**
- **Finance**
- **GPs**
- **Health care planning**
- **IT support**
- **Laboratory staff**
- **Managers**
- **Other specialists**
- **Patients**
- **Pharmacists**
- **Podiatrists**
- **Politicians**
- **Practice nurses**
- **Psychologists**
- **Public Health**
- **Retinal screeners**

Different systems of care

- **Total neglect:**
 - Nobody does anything for anyone
- **Random care:**
 - Most people do something for somebody
- **Partial total care:**
 - Some people do everything for some (sometimes twice) and nothing for the rest

Different systems of care

- **Total partial care:**
 - **Everybody does something for everyone, but not everything**
- **Partial shared partial care (shared neglect):**
 - **People hope someone else will do what they don't. In theory everyone gets everything, but doesn't.**
- **Total integrated care:**
 - **Everyone co-operates to ensure everything is done for everybody**


Evolution of Diabetes Dataset

**The Care of Diabetic Patients
in
Scotland**

Prevention of Visual Impairment
Incorporating a report on a recommended
minimum data set for collection in diabetic patients

A National Clinical Guideline
recommended for use
in
Scotland
by the
Scottish Intercollegiate
Guidelines Network

Pilot Edition
March 1996

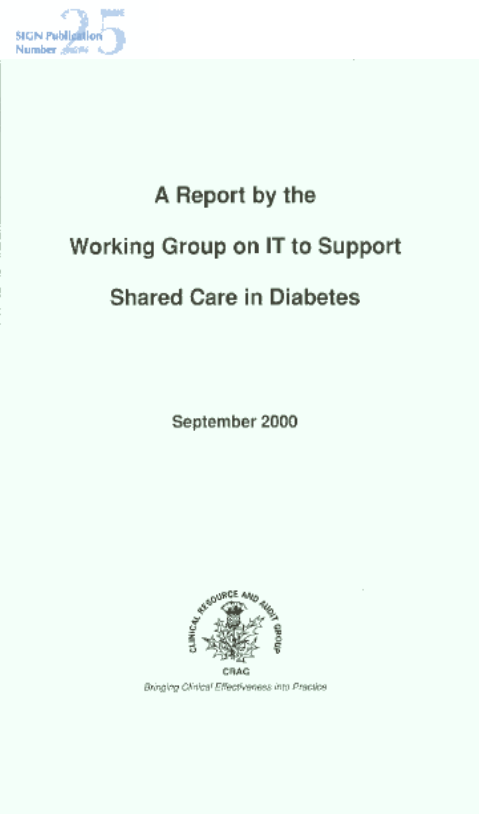


S I G N
Getting validated guidelines into local practice

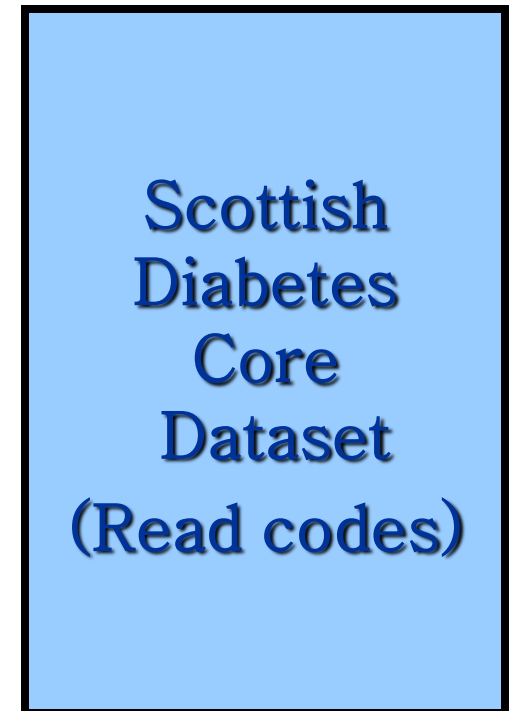
**March
1996**



**June
1998**



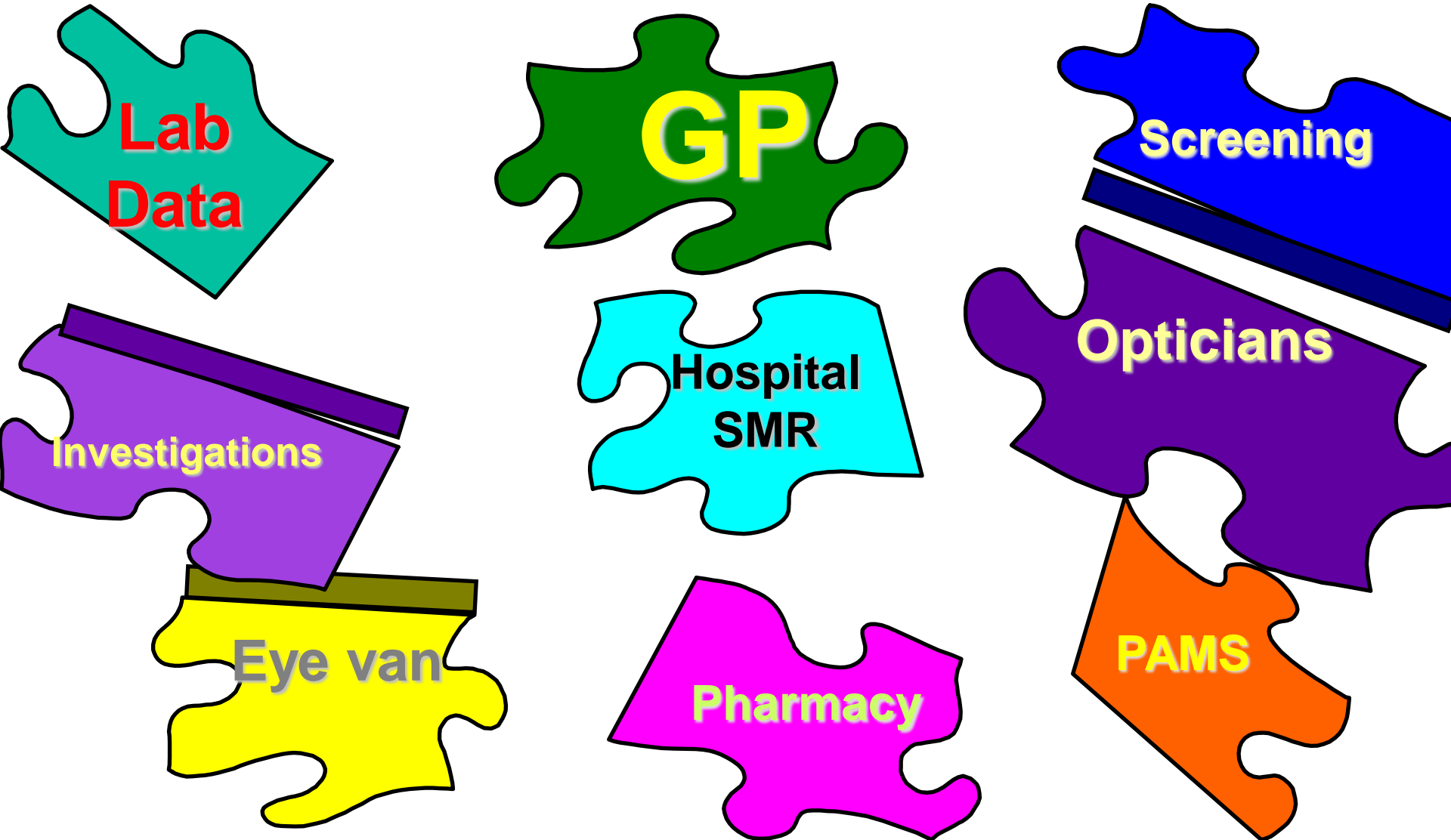
**September
2000**



**November
2002**

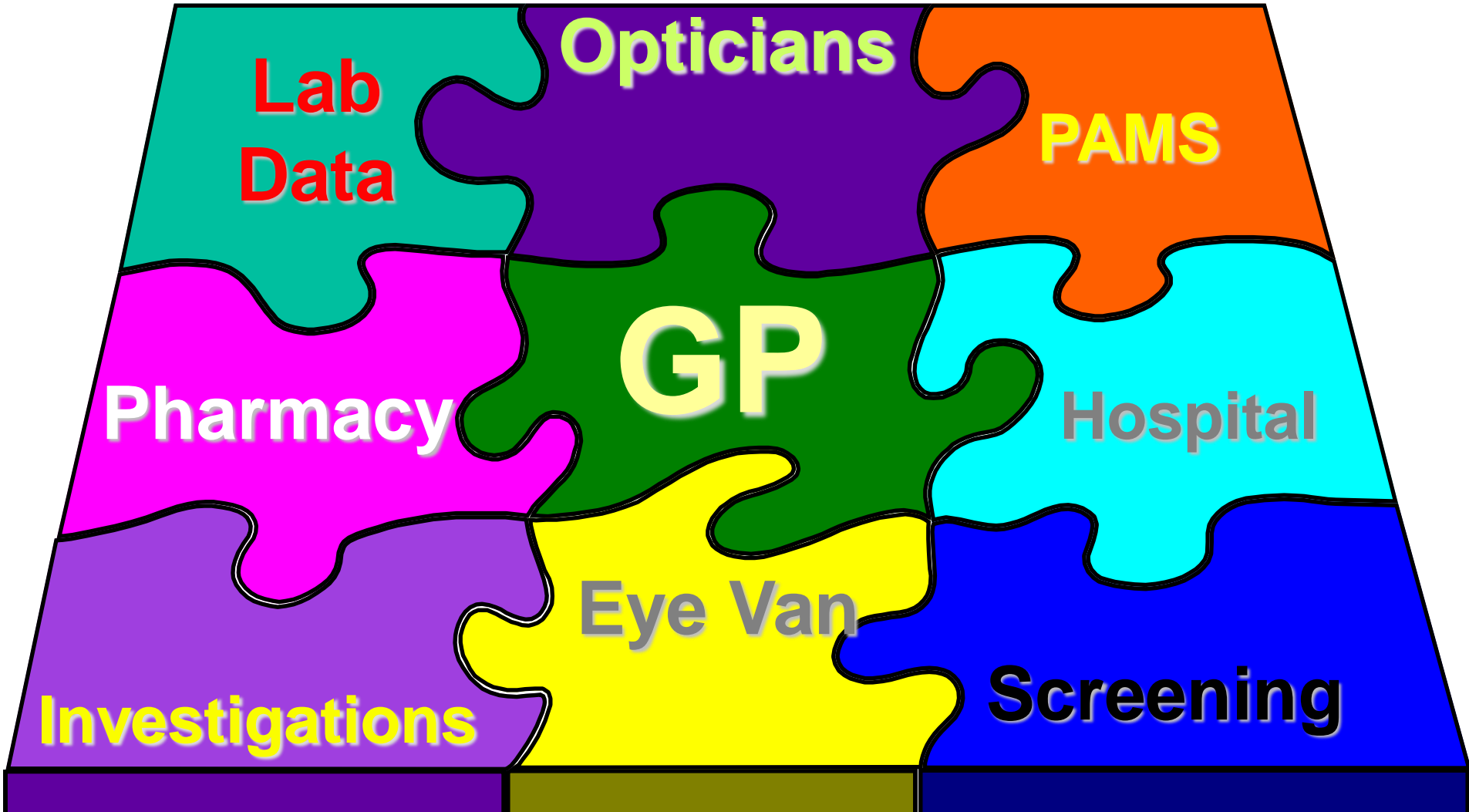
Data, Data everywhere

But not accessible




Linking the Data

Vital for Seamless Care



Scottish Diabetes Survey

 SCOTTISH EXECUTIVE
Health Department

NHS
HDL (2000) 12

Dear Colleague

Scottish Diabetes Survey

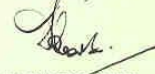
Summary

1. The Scottish Executive remains committed to improving the health of patients with diabetes. One of the key steps in achieving this objective is to improve the availability of data, particularly as many of the complications of diabetes can be prevented or delayed by effective monitoring of diabetic patients. This Circular outlines plans to compile a national picture of diabetes in Scotland through the central collation of information on diabetic patients and sets out the actions required by Health Boards, Trusts and individual clinicians. This builds upon the reviews of diabetes services undertaken by Health Boards and Trusts in response to MEL(1998)63.

Action

2. Health Boards, in close collaboration with Trusts, are asked to submit data on all diabetic patients within their area. The first survey of patients with diabetes should be undertaken on **31 March 2001** and data should be submitted to ISD.
3. Health Boards should ensure that there is a register of patients with diabetes in their health board area. A named individual should be appointed at Health Board level to discharge this responsibility.
4. The Health Department will establish a Scottish Diabetes Survey Monitoring Group to evaluate, on the basis of the national survey, the progress of Trusts and Health Boards in delivering diabetes services to the populations they serve and to monitor Scotland's performance in meeting the St Vincent Declaration targets.
5. The attached paper sets out further information about the diabetes survey – why it is being carried out, which data are required and how the information will be used.
6. This HDL is available on the Scottish Health on the Web (SHOW) web site: <http://www.show.scot.nhs.uk/rag>.

Yours sincerely


SIR DAVID CARTER
Chief Medical Officer


28th September 2000

Addresses

For action:
General Managers and Directors of Public Health, Health Boards
Chief Executives and Medical Directors, NHS Trusts

For information:
General Manager, CSA
Chief Executive, HEBS
Chief Executive, CSBS
General Manager, State Hospital
Executive Director, SCPMDE
Chief Officers, Local Health Councils

Enquiries to:
David Cline
Scottish Executive Health Department
Room 153
St Andrew's House
EDINBURGH
EH1 3DG
Tel: 0131-244 2235
Fax: 0131-244 2989
Email: David.Cline@scotland.gov.uk

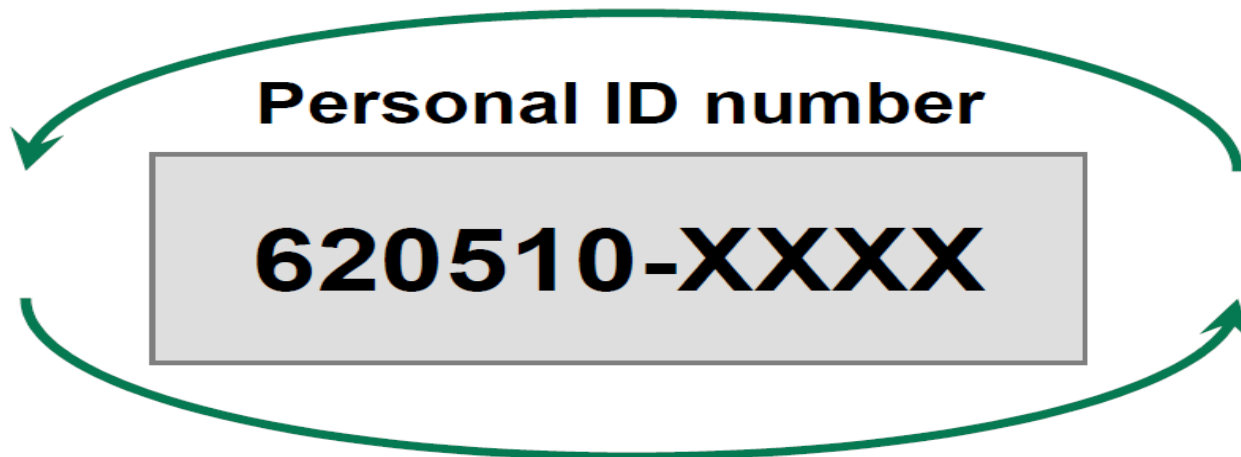


ISBN 1-84268-620-8

“Health boards should ensure that there is a register of patients with diabetes in their health board area.”

**Chief Medical Officer
September 2000
HDL(2000)12**


The Swedish National Diabetes Register



the patient is always traceable

The Swedish National Diabetes Register

Reporting to NDR

	Personnummer inkl. sekel 19560929-5509	Visa specifik information om din vårdenhet.	Startsidan						
	Rapportera	Komplettera	Diabetesprofil	Översikt	Söklista	Statistik	Admin	Logga ut	
Hjälp									
Besöksdatum	2013-11-08	Vårdgivar-id	490	Personnummer	19560929-5509				
Datum för senaste besök: 2013-10-17									
1. Debut, årtal									
2000									
2. Typ av diabetes (klinisk bedömning)									
Typ 2 diabetes (inkl MODY)									
3a. Diabetesbehandling									
Insulin, vilket/vilka		Tabletter, vilket/vilka							
Tabletter		Välj preparat		Ta bort		Välj tablett		Ta bort	
3b. Metod att ge insulin									
4. HbA1c									
mmol/mol									
5. Kroppsvikt									
kg									
6. Kroppslängd									
178 cm									
BMI=									
Beräkna BMI									
7. Midjeomfång									
cm									
8. Blodtryck									
Systoliskt blodtryck		mm Hg							
Diastoliskt blodtryck		mm Hg							



Unique software system merging electronic data



Today's Snapshot



Yesterday's Snapshot

Snapshots compared



*New/Altered/Deleted
records passed
securely to SCI-DC*

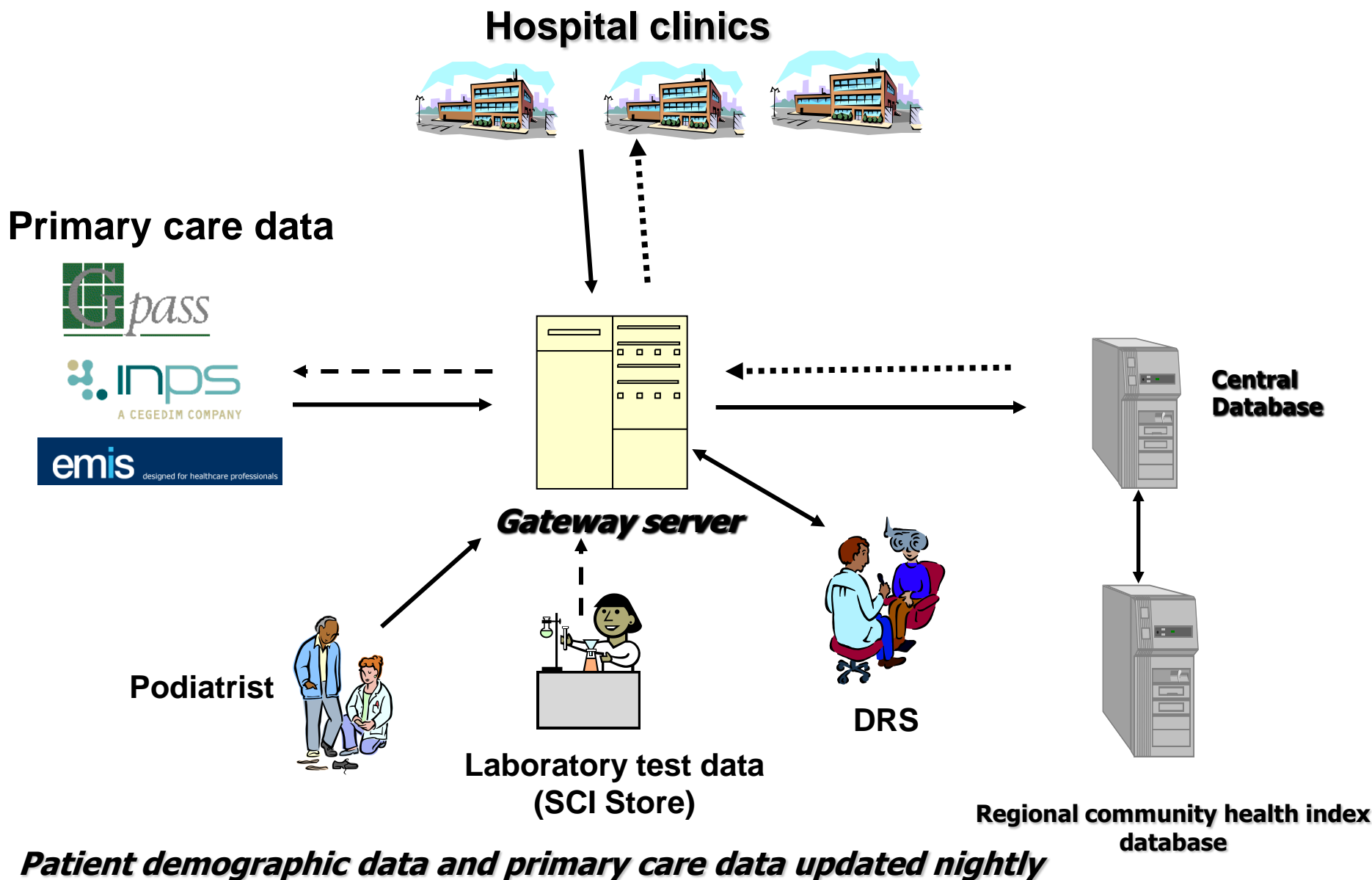


Central Database

GENERIC Importer / Exporter

(GENIE)

Scottish Care Information – Diabetes Collaboration (SCI-DC): overview



Principles

- Understand the dataset
- Collect data once and use many times
- Rubbish in rubbish out
- Best way to have data is as an automatic by-product of routine clinical care
 - e.g. clinic letter
 - Not extra data collection for future audit

Reinhard Holl

Paediatric Registries

Austrian/German DPV registry

nationwide basis since 1995



Interaction with

T1DExchange registry

NPDA England/Wales

SweddiabKids registry

Joint analyses, publications



T1D Exchange



Hvidoere study group

Member during the early years



Data management for SWEET group

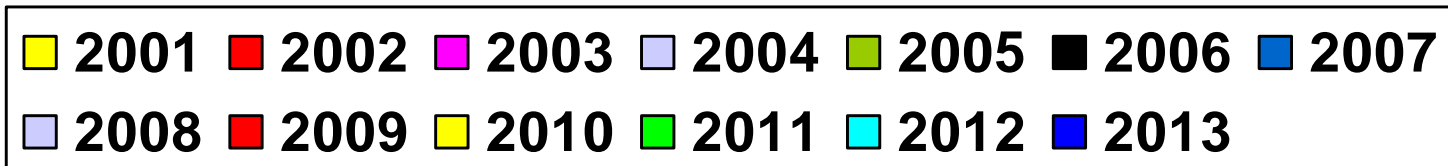
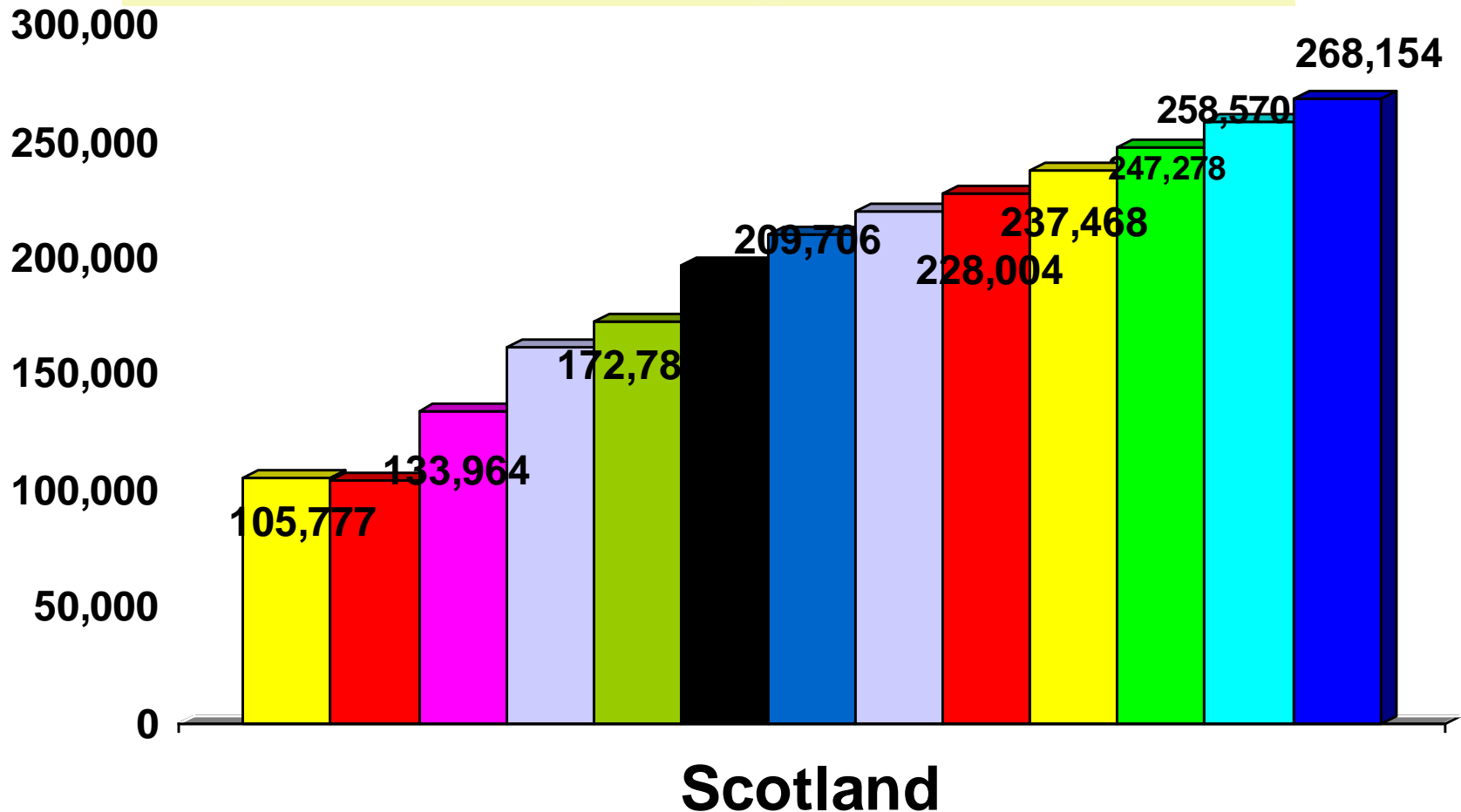
started June 2014



Improving care (Influence)

- Scotland
 - Practice
 - NHS Board
 - Patient (MDMW)
 - Clinic
 - Ward
 - International
- Right data in good format when required

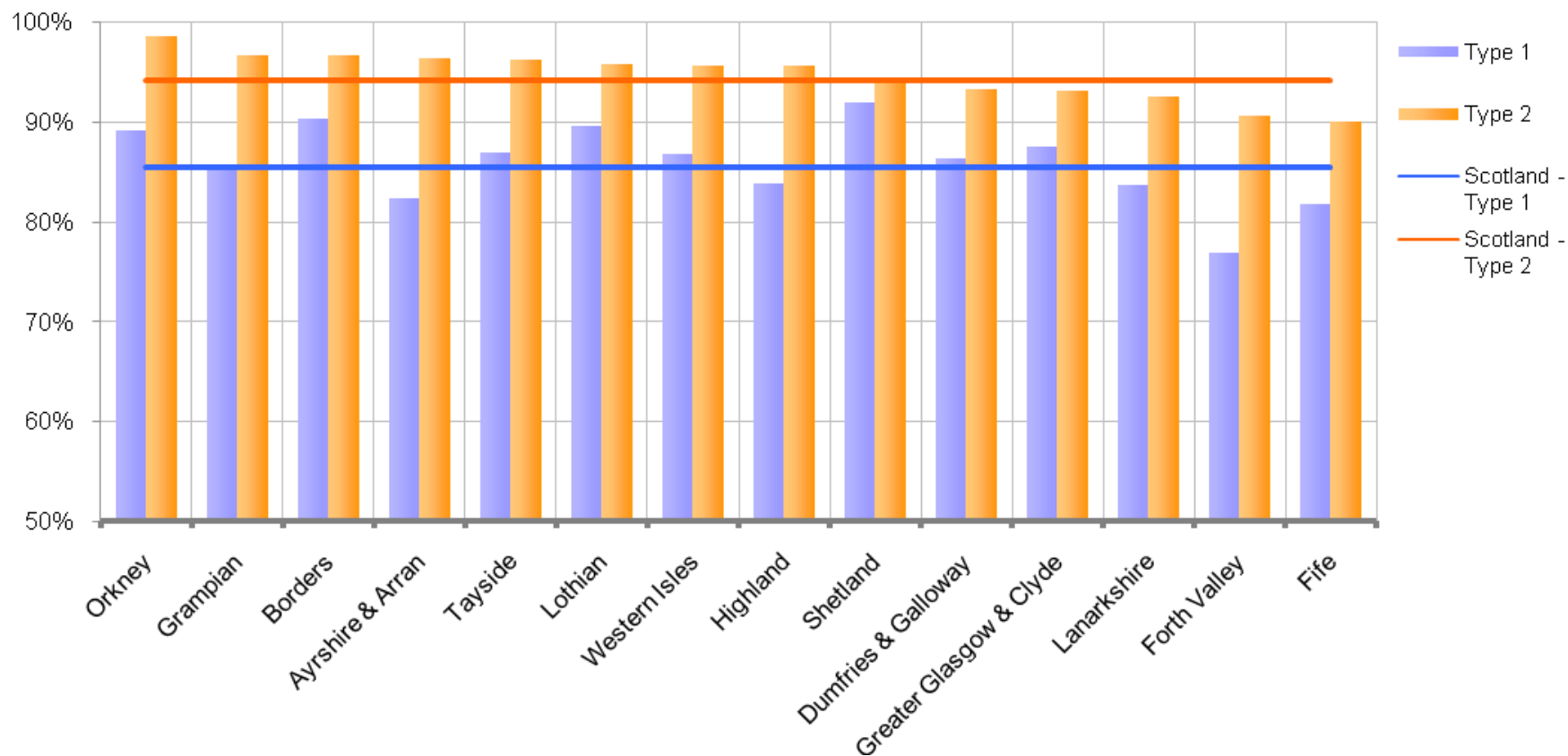
Scottish Diabetes Survey 2001-2013: Number of patients



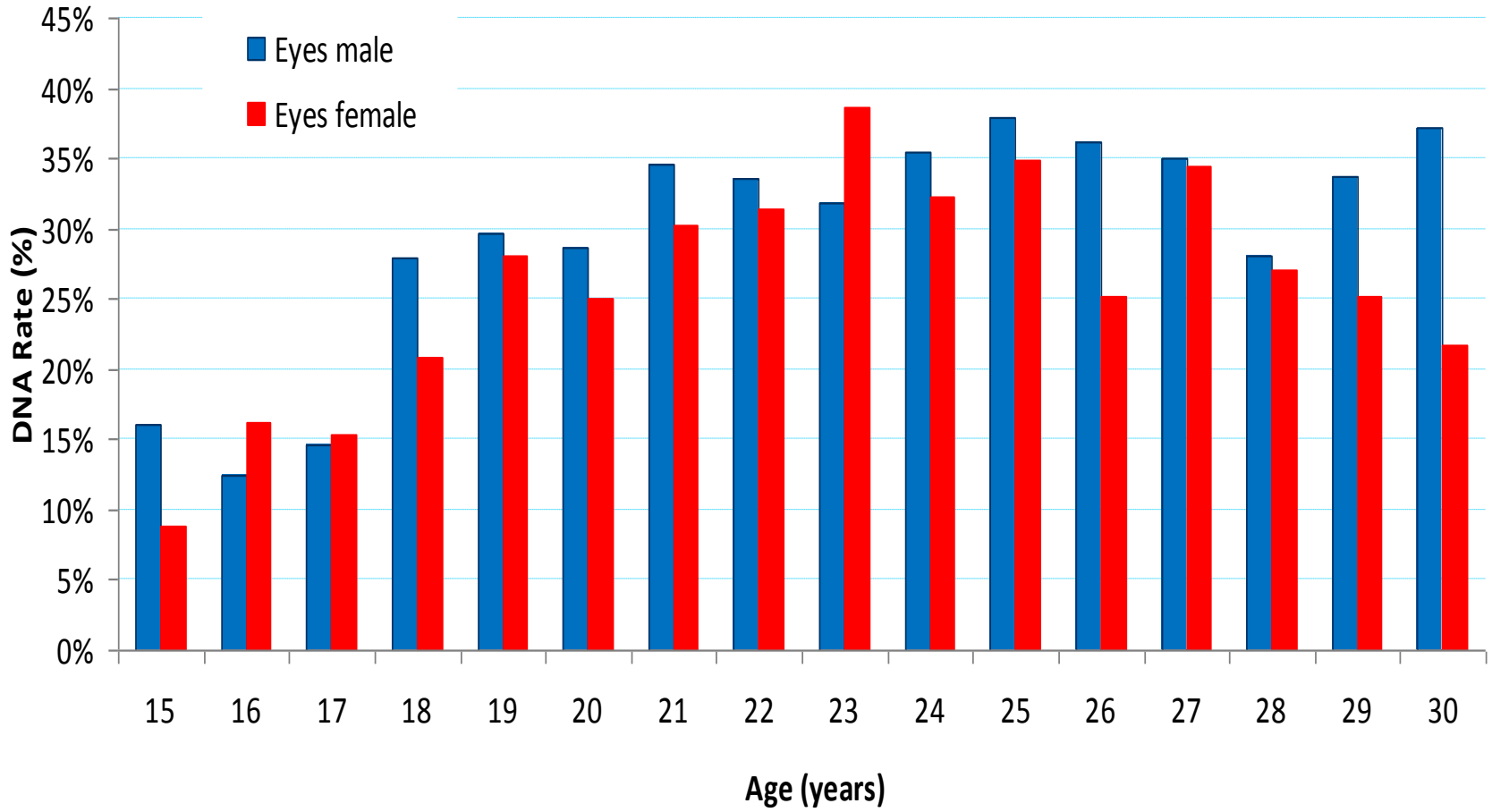
Type 2 diabetes: incidence rate (per 100,000 population per year) Scotland.

Age	2009		2010		2011		2012		2013	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
Under 10	2	0	0	0	0	0	0	0	1	0
10 to 19	22	4	18	3	10	2	21	3	8	1
20 to 29	164	24	166	24	163	23	208	29	178	25
30 to 39	797	120	755	116	730	113	939	146	810	124
40 to 49	2,667	335	2555	321	2552	322	2733	347	2,570	323
50 to 59	4411	653	4787	629	4106	595	4567	650	4,387	606
60 to 69	5286	944	4870	851	4741	814	4943	833	5,023	826
Over 69	5286	867	4925	799	4667	747	4596	729	4,876	762
Total	18627	360	17576	338	16969	325	18007	343	17,853	336

Figure 11. Percentage of people with diabetes (by diabetes type) with a recording of BP in previous 15 months, by NHS Board (horizontal lines show levels for Scotland as a whole); ranked by figures for type 2

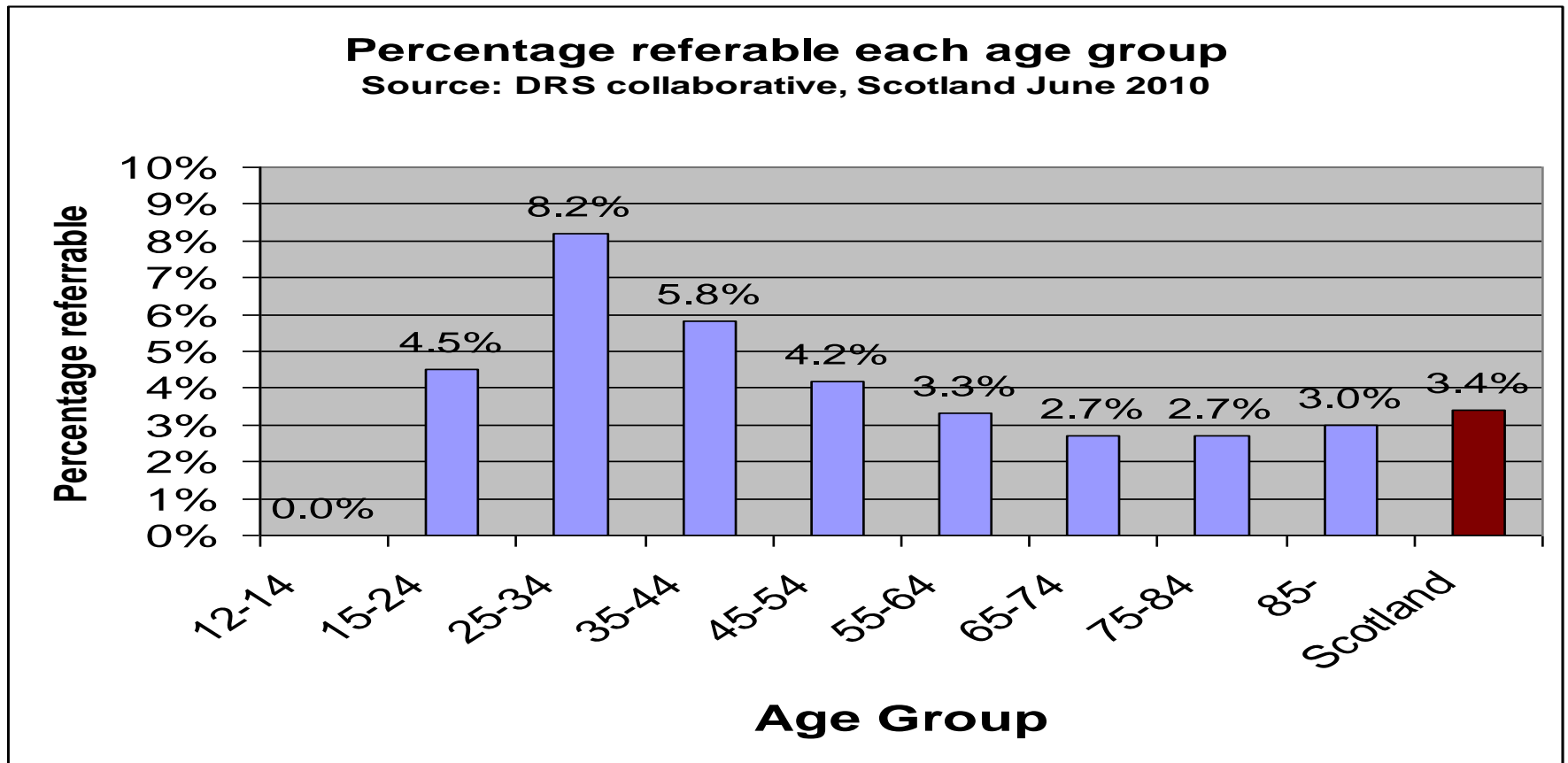


DNA Rate for eye tests by age (all HBs for 2010)

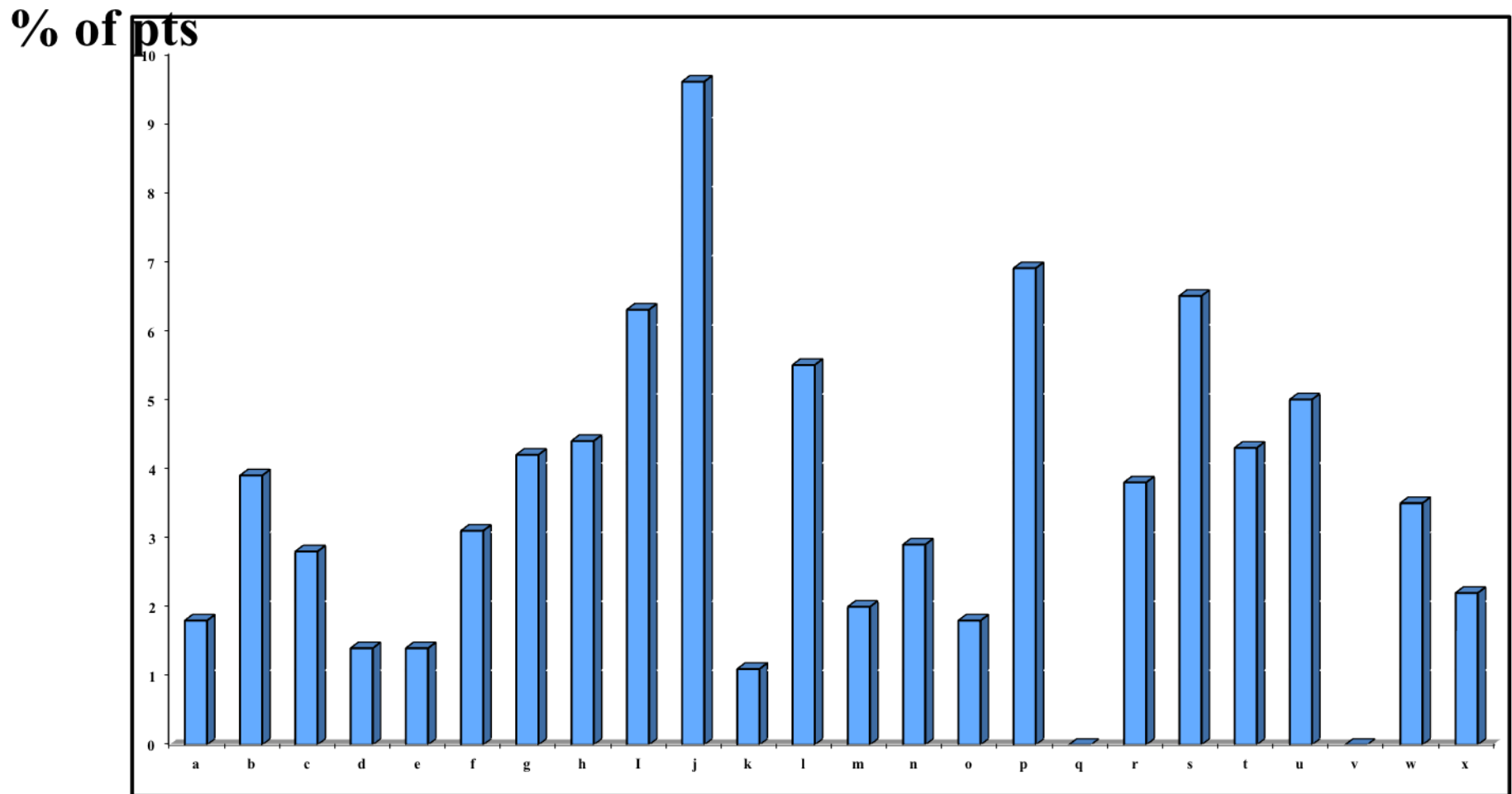


Referable retinopathy

- Age group



HbA1c not recorded by practice



Practice

ARCHIBALD MACKIE

My HbA1c History



ChartDirector (unregistered) from www.advsofteng.com

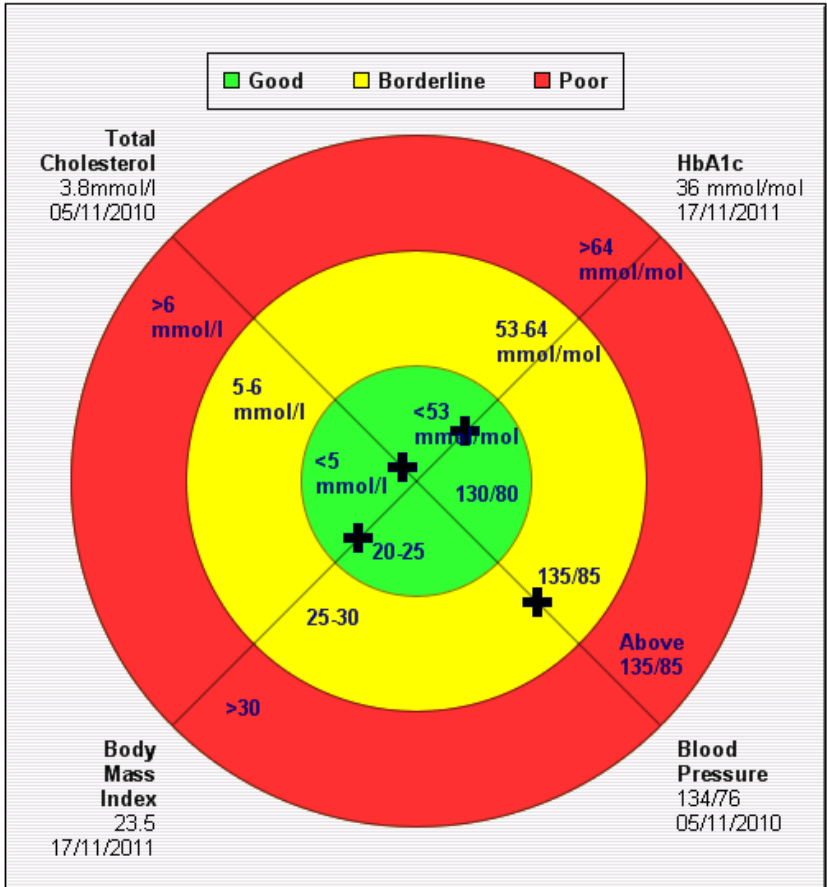
Date	IFCC HbA1c (mmol/mol)	DCCT HbA1c (%)	Source
20/01/2012	45.0	6.3%	Tayside Practice 1 - GPASS, Primary Care
27/05/2011	44.0	6.2%	Tayside Practice 1 - GPASS, Primary Care
21/08/2010	44.0	6.2%	Tayside Practice 1 - GPASS, Primary Care
08/08/2009	41.0	5.9%	Tayside Practice 1 - GPASS, Primary Care
12/07/2008	45.0	6.3%	Tayside Practice 1 - GPASS, Primary Care
24/08/2007	43.0	6.1%	Tayside Practice 1 - GPASS, Primary Care

[logout](#)

[my personal details](#) | [my lifestyle](#) | [my test results](#) | [my eye screening](#) | [my foot screening](#) | [my medication](#) | [my diary](#) | [my preferences](#) | [my care measures](#)

ARCHIBALD MACKIE

My Target Chart

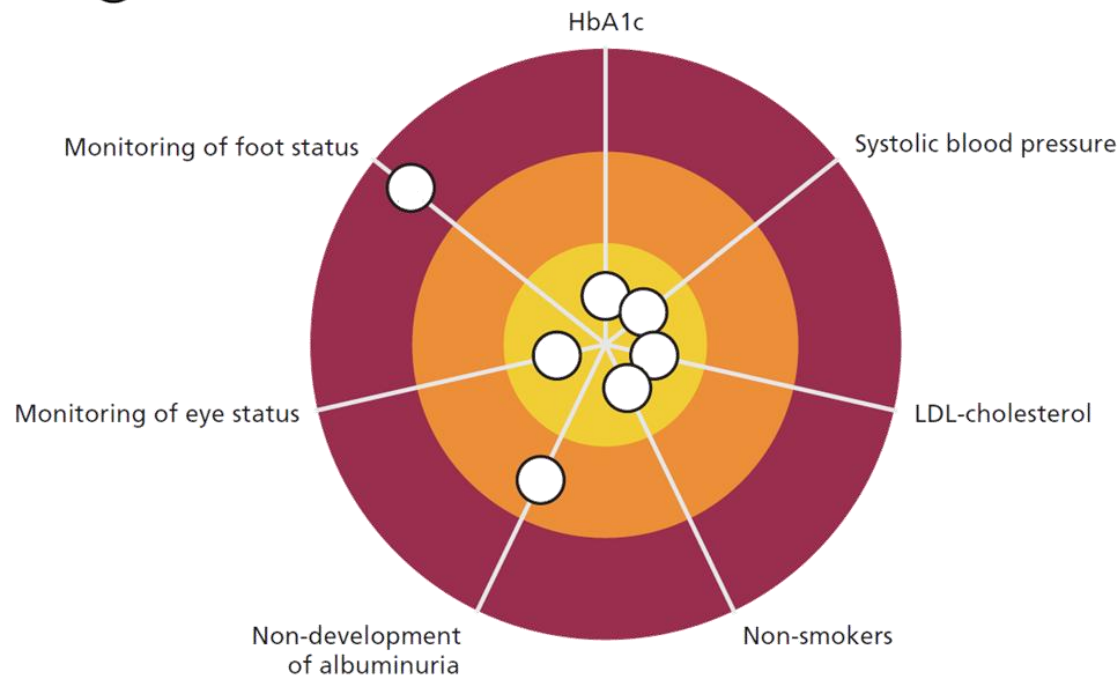


Easy overview on hospital level

Sahlgrenska University Hospital/Sahlgrenska

Mean age 46, n=1,161

○ 2012



The Swedish National Diabetes Register

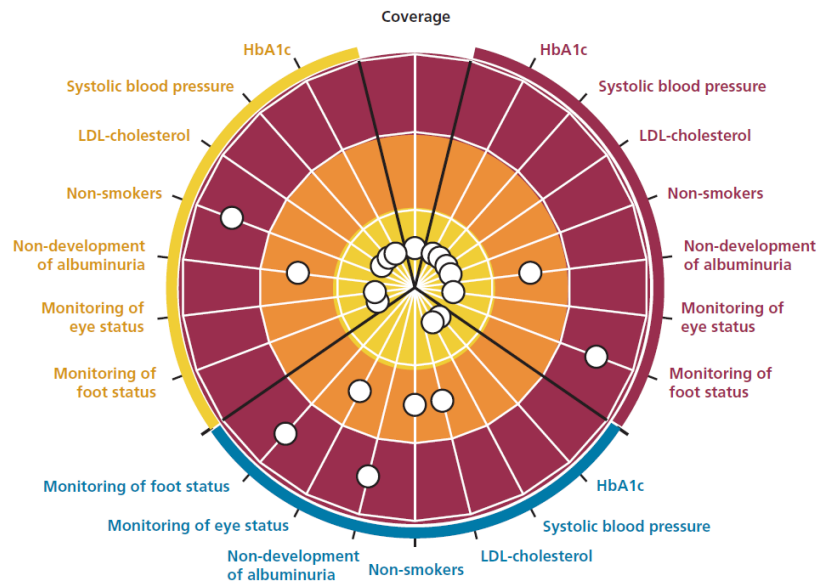
Easy overview on a county level

Västra Götaland

Hospital, type 1 diabetes
N = 6,435
Mean age = 45.5
Mean duration = 22.7
Men = 56.6%

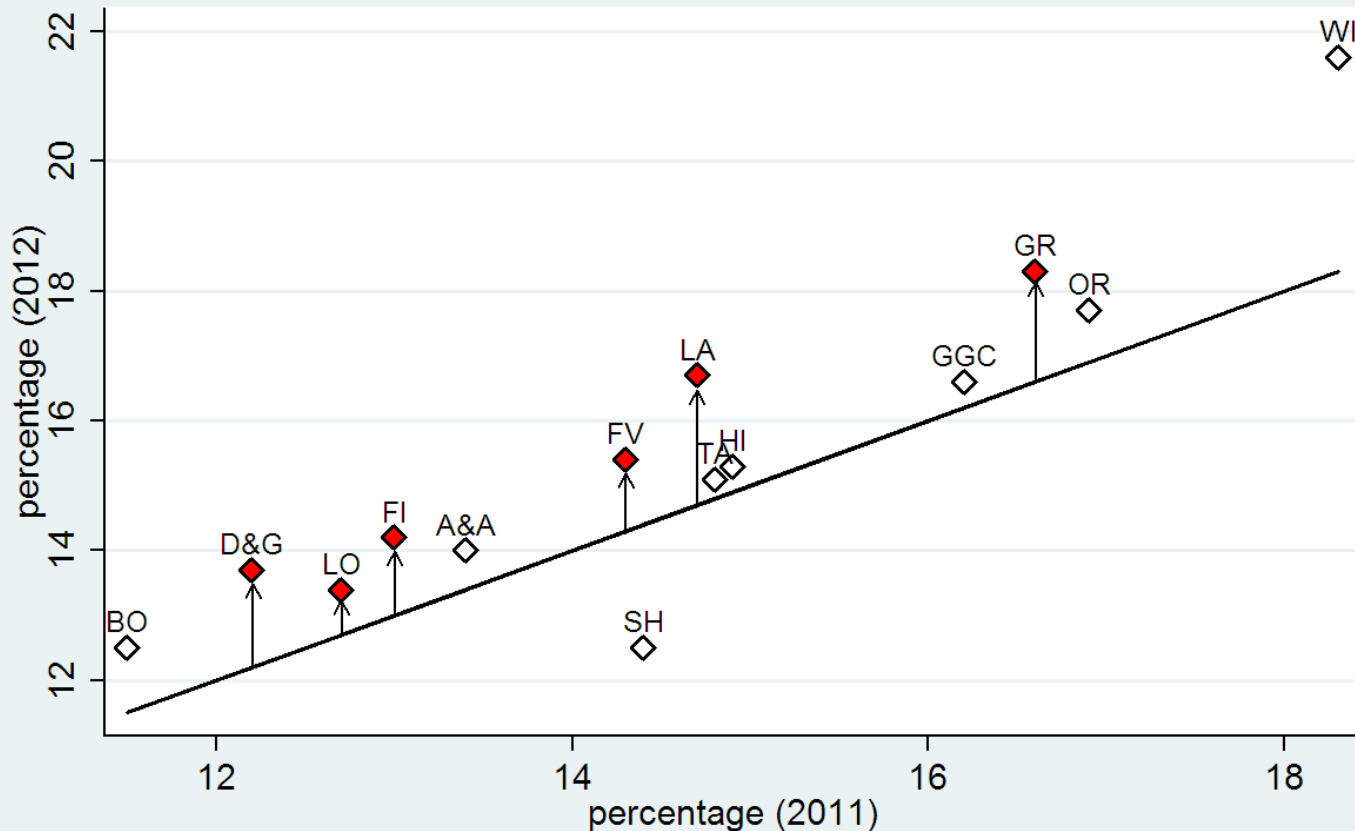
Hospital, type 2 diabetes
N = 2,337
Mean age = 63.7
Mean duration = 15.4
Men = 67.6%

Primary care
N = 56,640
Mean age = 68.5
Mean duration = 9.0
Men = 55.9%



Change over time

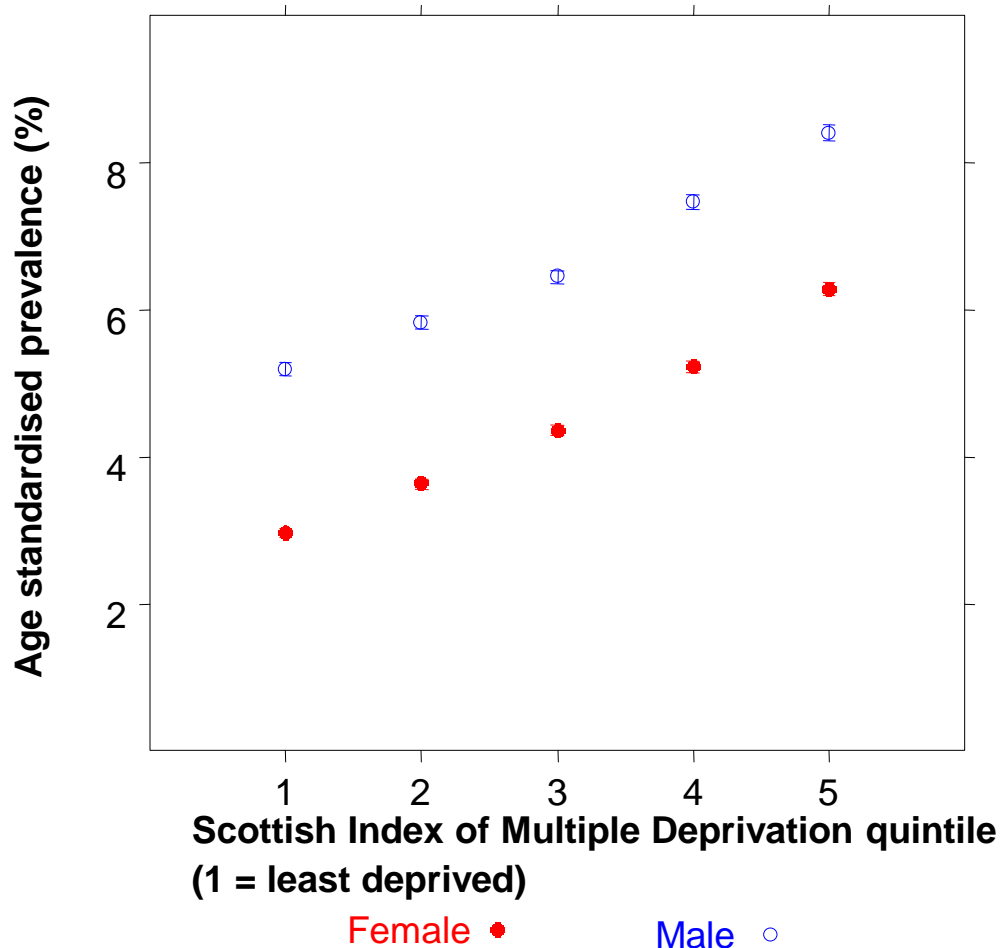
Table 23: Type 2 diabetes - percentage with HbA1c >75mmol/mol (9%)
restricted to those with HbA1c recorded in last 15 months



Note: diagonal line shows no change; red markers indicate significant change

Diabetes epidemiology

Age-standardised* prevalence of T2DM among 35-84 year olds in Scotland by area based socio-economic status, 2007



RR for most vs least deprived:

1.58 (1.20-2.07) for men

2.00 (1.52 to 2.62) for women

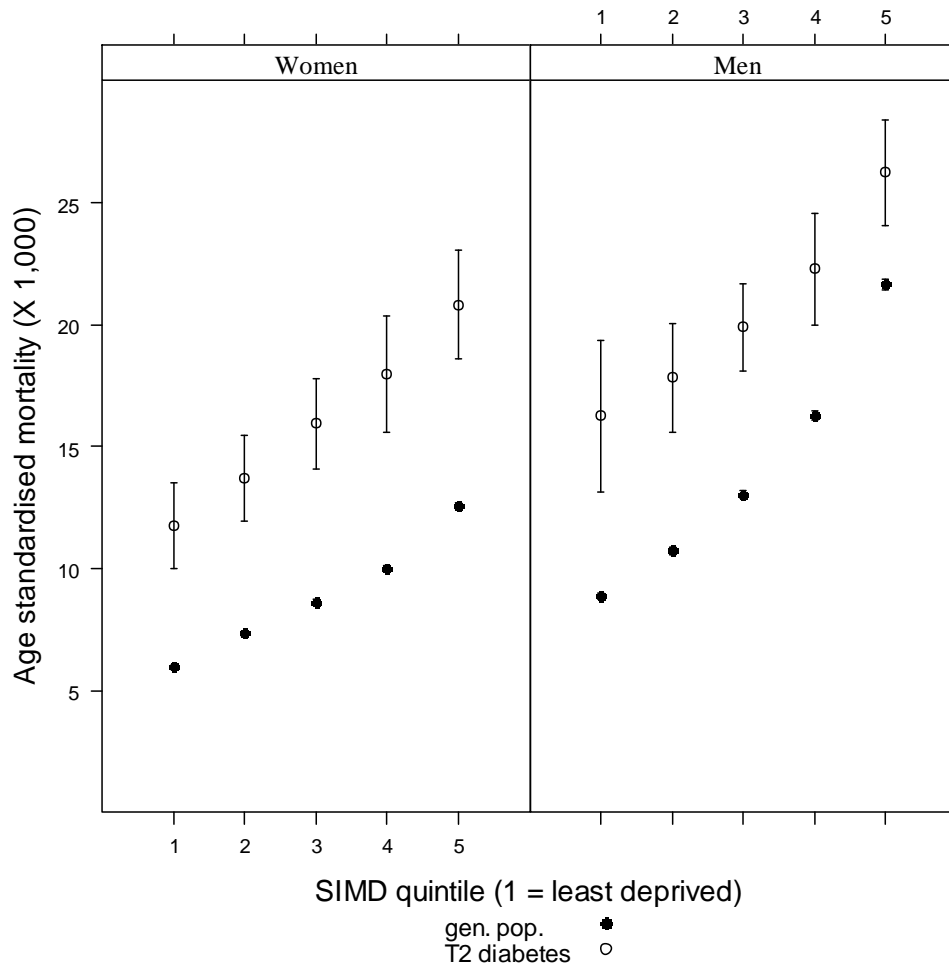
* Using European standard population

Diabetes and mortality

Scotland 2001-7

	Age-adjusted absolute mortality (per 1000 PY)		Age-adjusted relative risk
Sex	Type 2 diabetes	No diabetes	
Men	19.5 (19.1 – 19.9)	13.4 (13.3 – 13.5)	1.38 (1.28 to 1.48)
Women	15.8 (15.4-16.2)	8.45 (8.40-8.50)	1.67 (1.58 to 1.77)

Age-standardised all-cause mortality 2001-7: T2DM vs. non-diabetic population by sex and SIMD quintile



Relative risks higher for

- women than men
- younger than older people
- affluent than deprived

Relative risks generally higher if absolute risk lower.

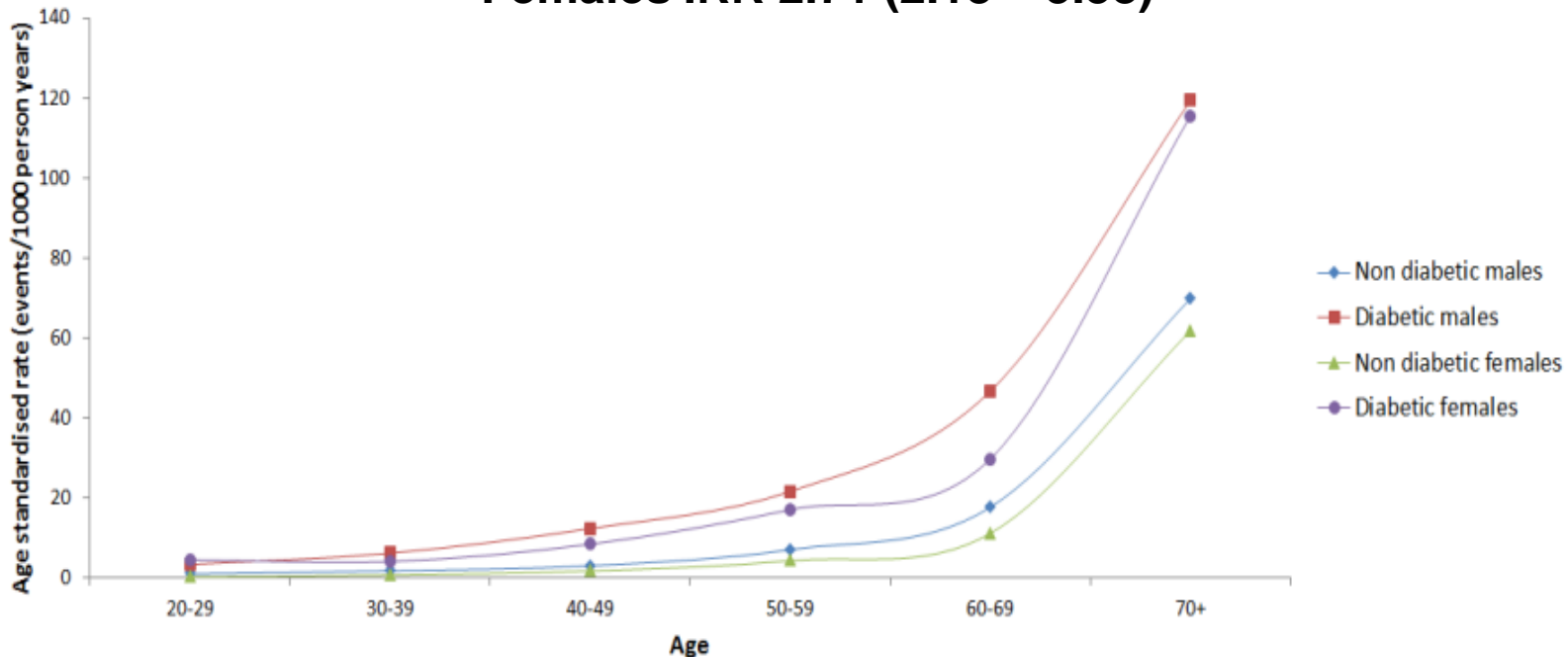
Impact of poor glycaemic control on hospital admissions – type 1

- **HbA1c >10.8% vs HbA1c 7.5-8%**
 - Extra 2915 hospital admissions over 3 years
 - 2759 “diabetes related” group
 - 1616 “diabetic ketoacidosis”
- **“Extra” cost for those with HbA1c >10.8%**
 - £2.4m per annum for all admissions
 - £1.3m per annum for “extra” ketoacidosis admissions

Source: Govan L et al Diabetes Care. 2011;34(9):1992-7

Death Rates by Age : 21789 T1DM compared with 3.6 million Non DM

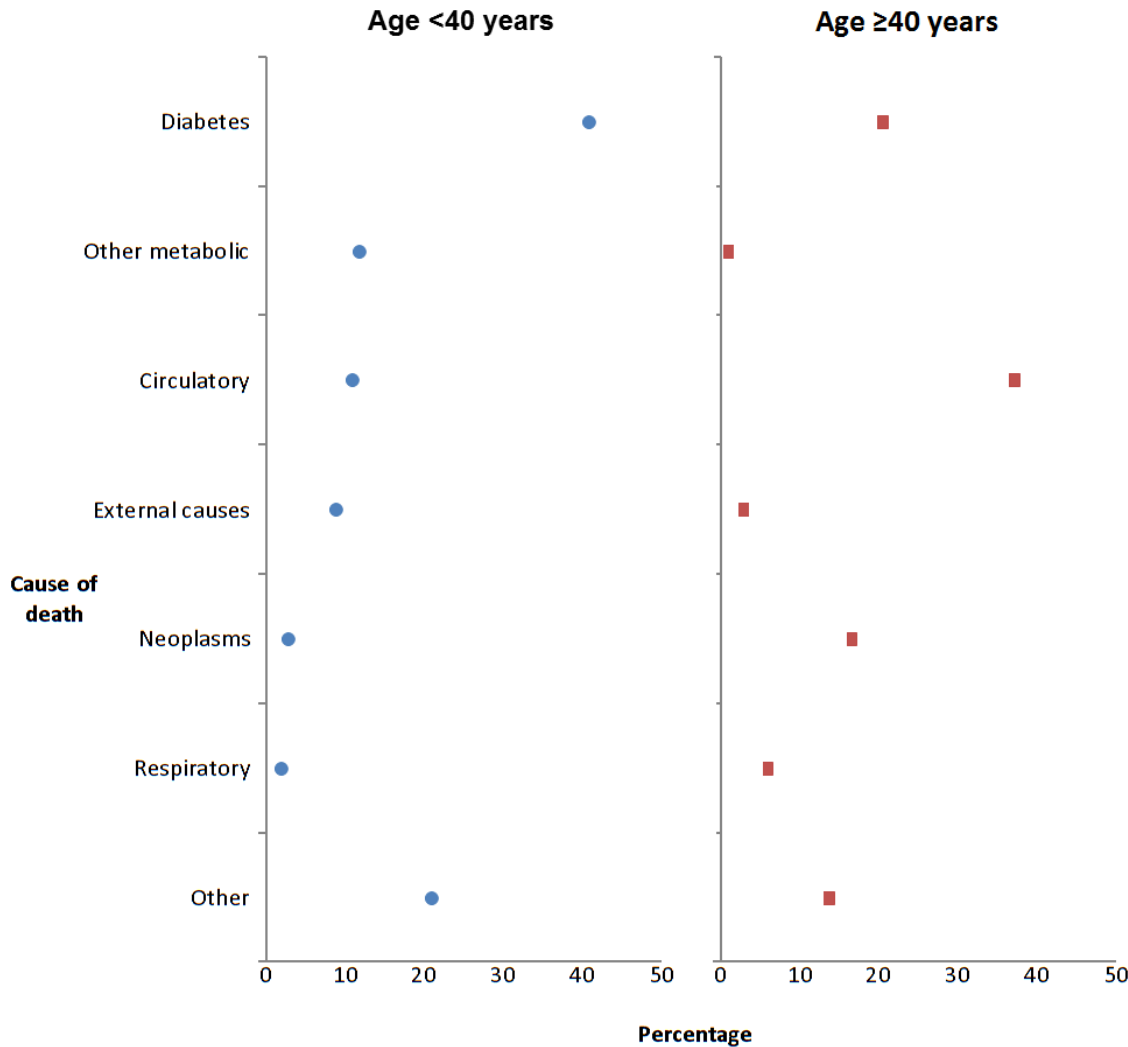
Total mortality
Males IRR 2.58 (2.23-2.98)
Females IRR 2.71 (2.18 – 3.38)



Much lower mortality relative risks than in earlier studies

*Livingstone...Colhoun for SDRN Epi Group
PloS Med 2012*

% of Deaths due to various Causes Causes by Age Among Those with Type 1 DM



Still high levels of early deaths directly from diabetes: about 12 deaths per year among those 10173 patients aged 20-40 yrs with underlying cause of death of hypo or hyperglycaemic crises:

Among those dying with coma over the three years the median preceding HbA1c was 8.65 (7.75 -10.65) and many had not had HbA1c for a few years

Lower limb amputation (diabetes, Scotland) 2004 to 2008

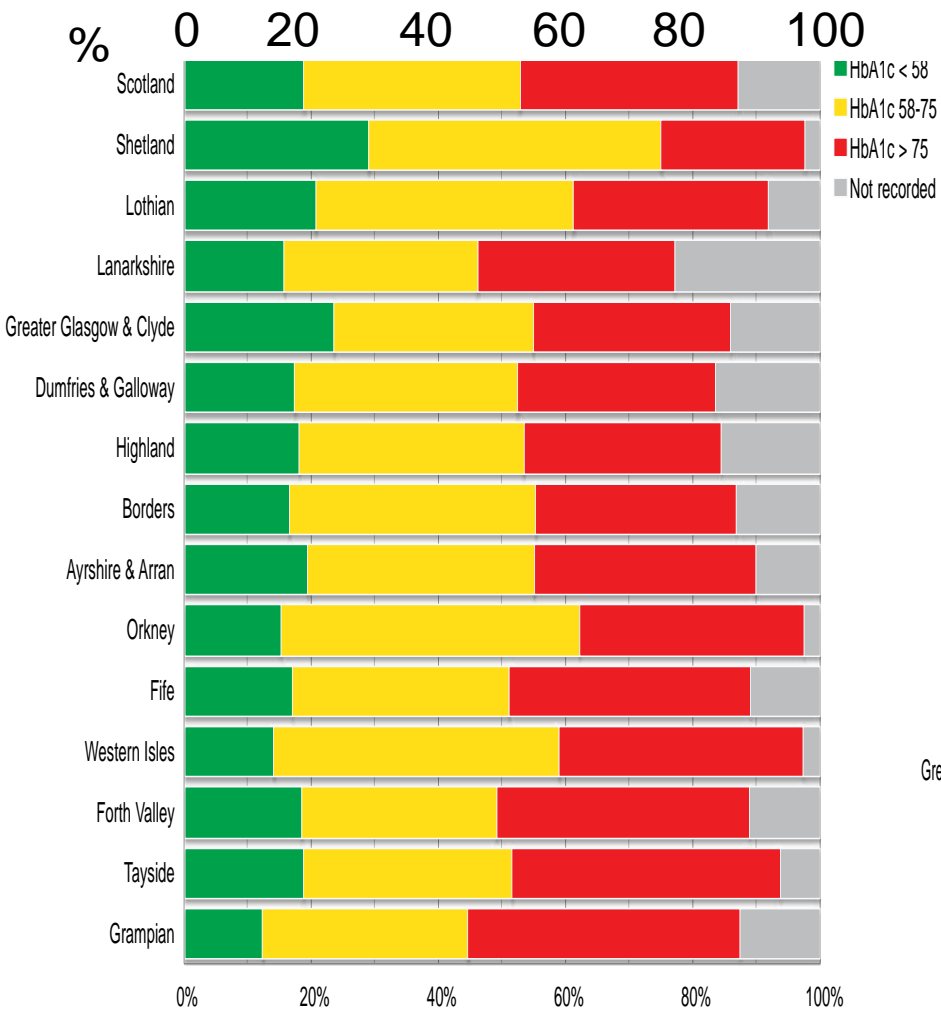
- 2,382 underwent a non-traumatic LEA between 2004 and 2008;
- 57.1% major LEAs.
- The incidence of any LEA decreased by 29.8% ($P < 0.001$).
- Major LEA rates decreased by 40.7% from 1.87 to 1.11 per 1,000 (2004 to 2008: $P < 0.001$).

A 1 % reduction in HbA1c

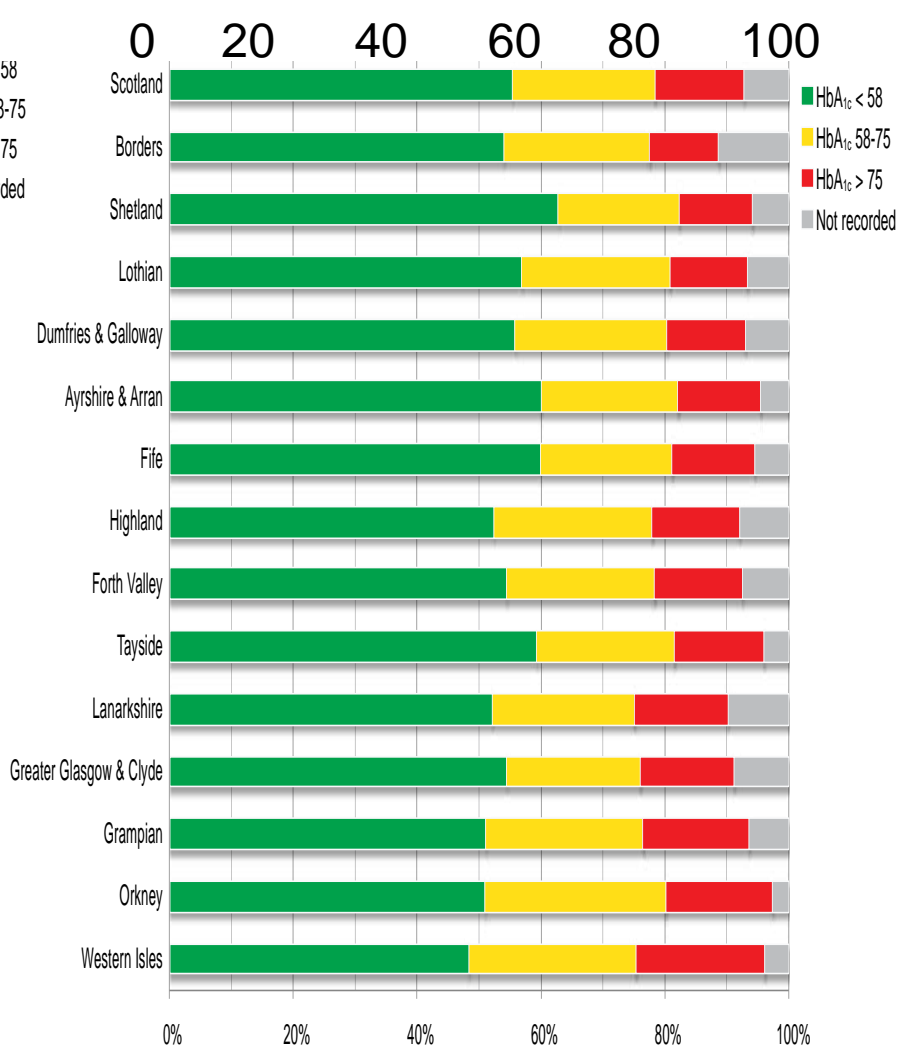
- For ten years
 - NNT to prevent three step change in retinopathy = 5.6
 - NNT to prevent microalbuminuria = 16.8
 - NNT to prevent clinical neuropathy = 16.8

James Walker

Glycaemic control in Scotland; 2012 Survey



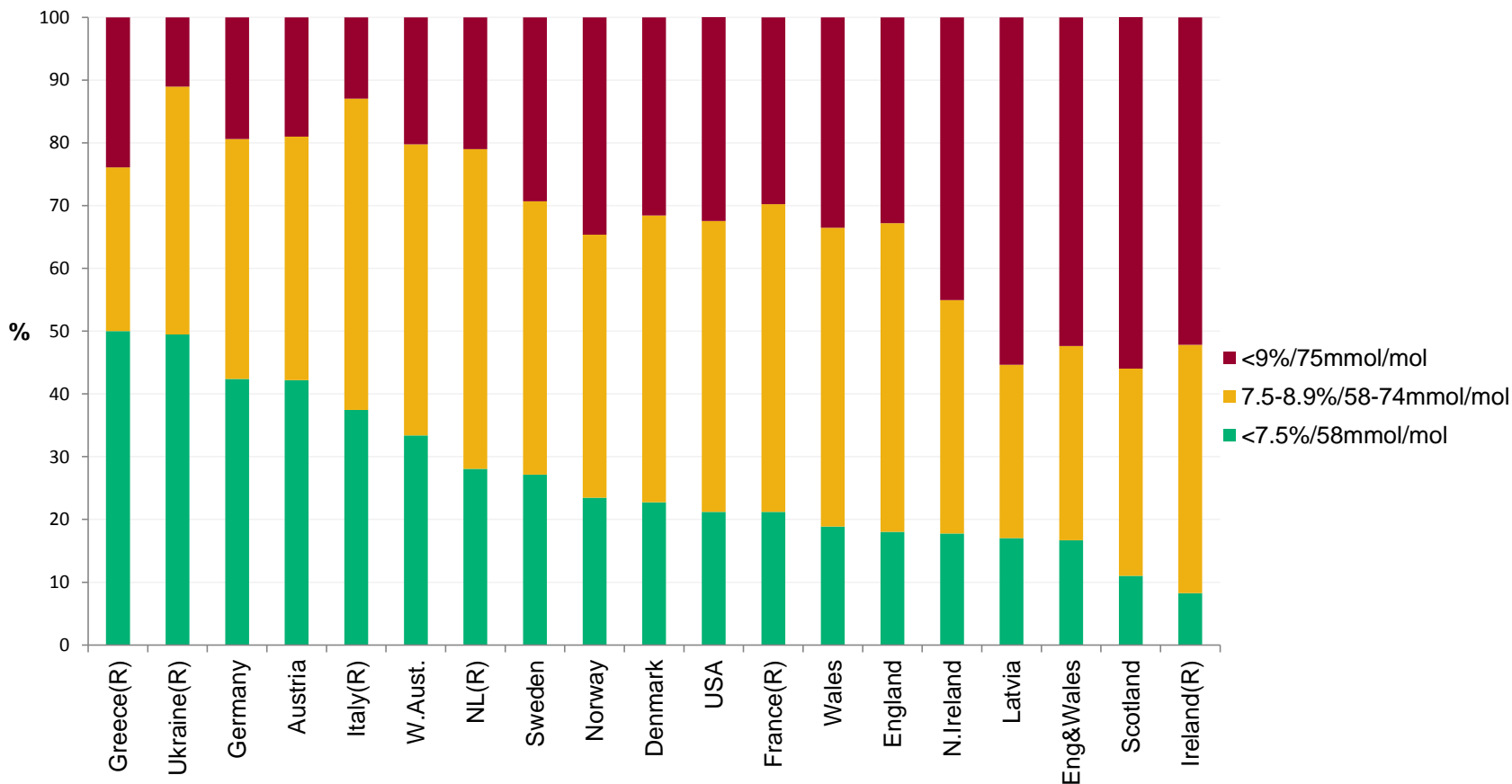
Type 1



Type 2

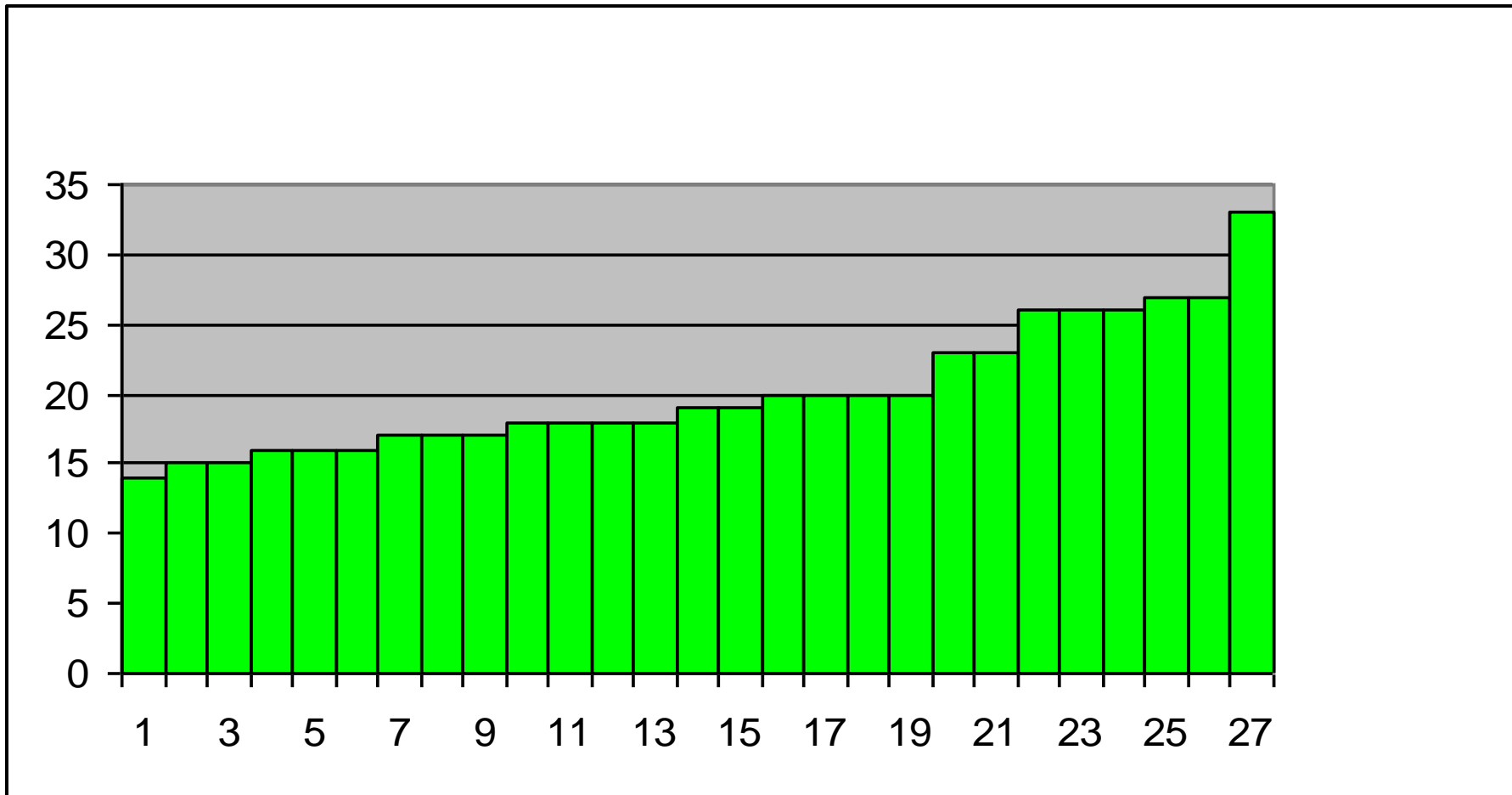
Diabetes control in young people aged under 25: comparators

International Quality of Care for Type 1 diabetes collaboration
(personal communication Sarah Wild, manuscript under consideration)



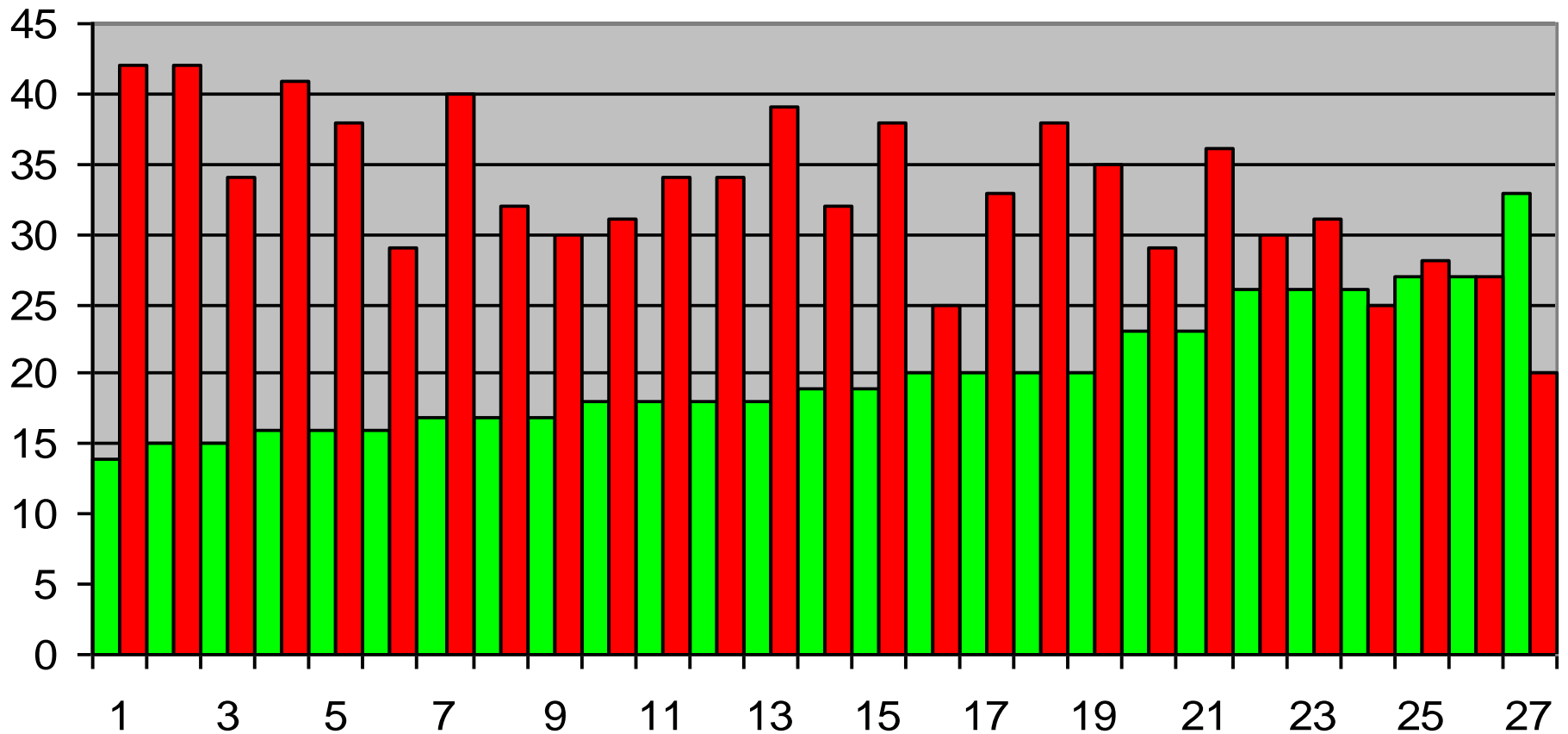
Percentage in each clinic with HbA1c <7.5 %

n = 17,253 (range 27 centres n = 164 to 1,555)

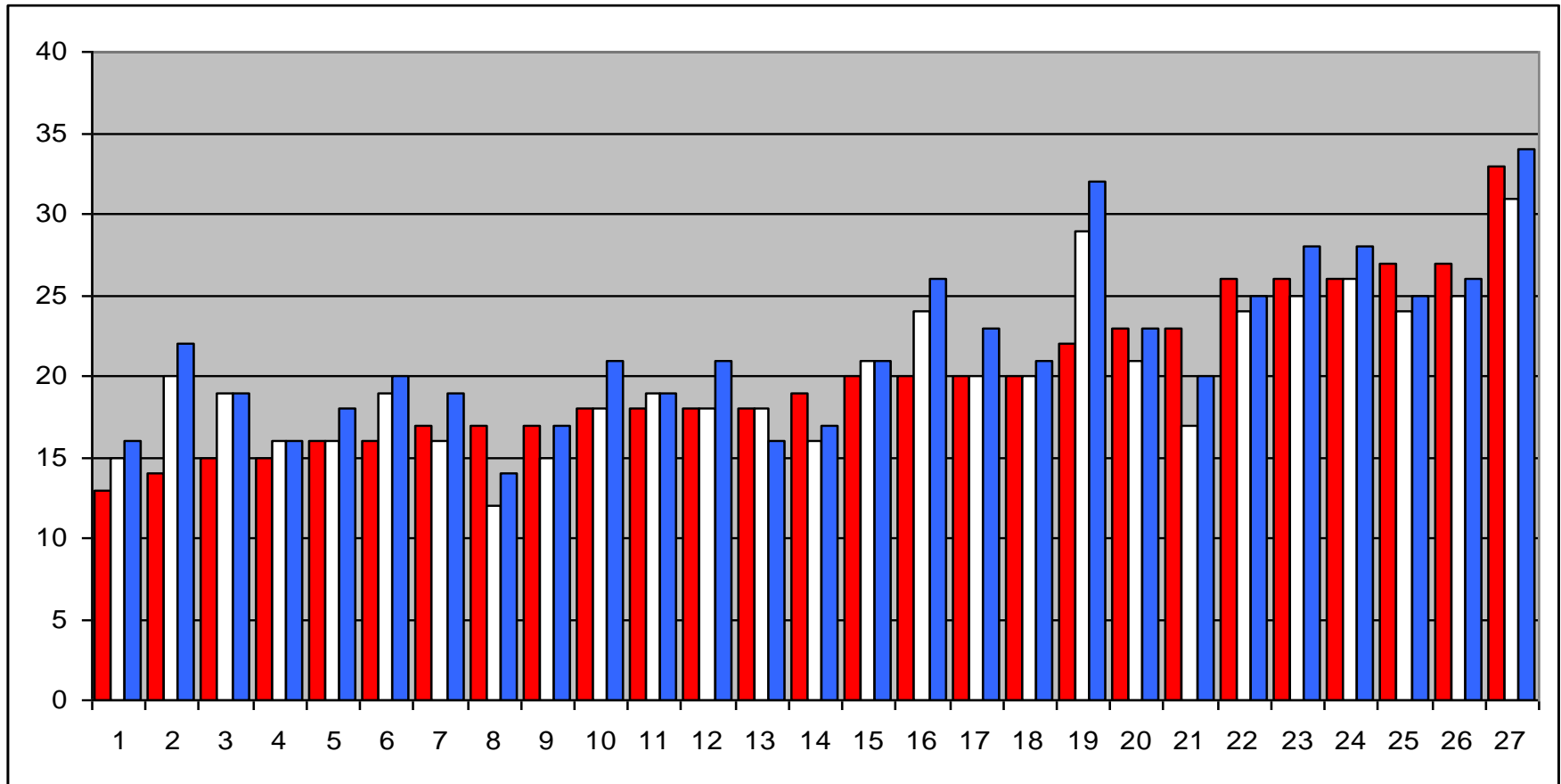


Range 14 to 33 %

Percentage in each clinic with HbA1c <7.5 % and >9.0 (ranked by <7.5 %)



Percentage of patients with HbA1c <7.5 %, ordered by result in Nov 2013



■ Nov 2013 □ Jun 2014 ■ Aug 2014

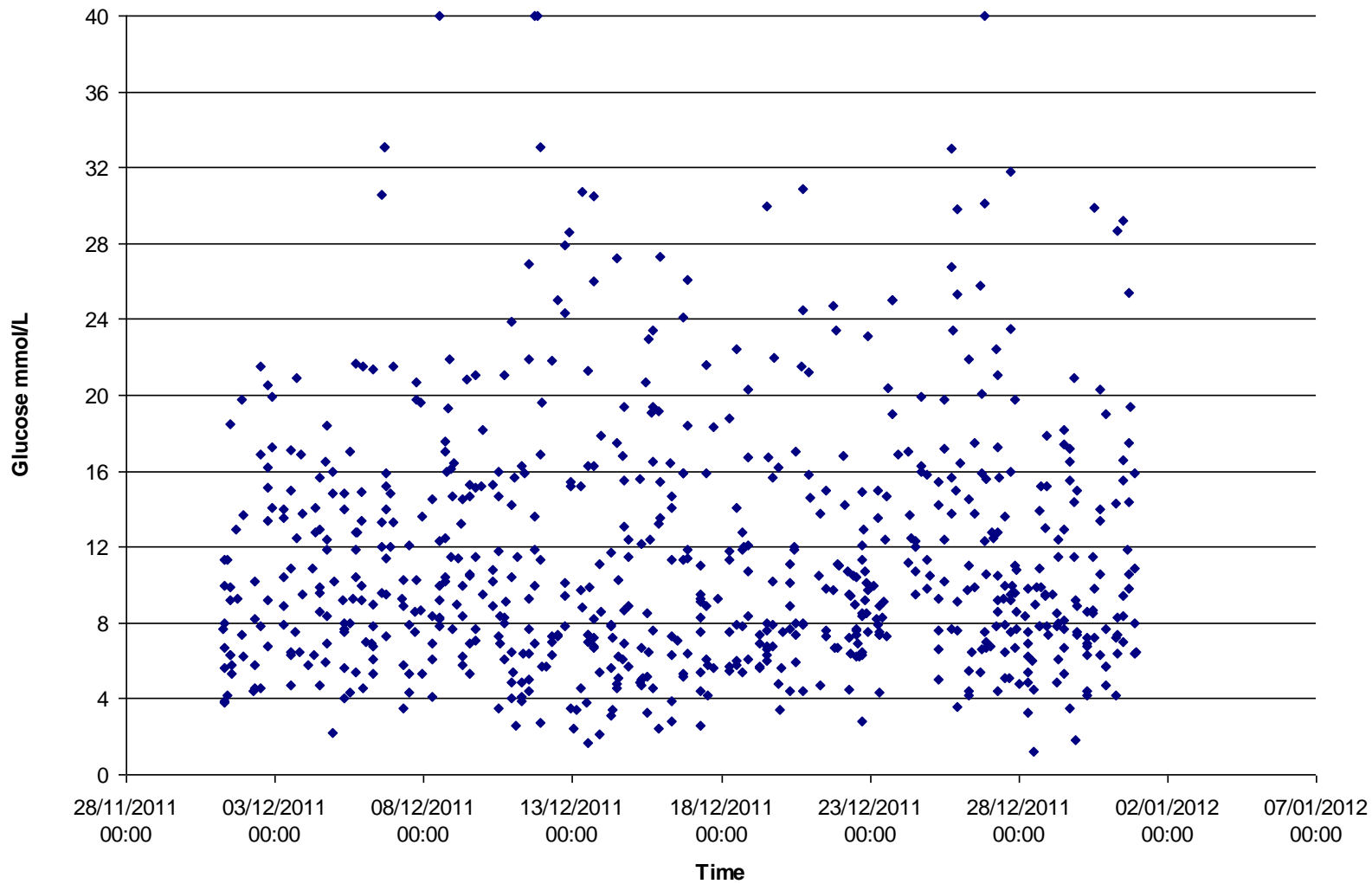
Summary

- Registries can influence diabetes care in many ways:
 - Design
 - Efficiency
 - Governance
 - Quality improvement
 - Improving understanding

Conclusion

- A diabetes registry is an essential element of any modern health care system

WARD 26 DEC 11
710 RESULTS, 4% <4, 36% >12



WARD 26 JUN 13
357 RESULTS, 2% <4, 21% >12

