Children's & Young Persons' Diabetes MCN

Dr Ian Craigie

RHC Glasgow

Conference 2019

Conference 2019 Documents, Presentations and Outcomes

AGENDA

Living with Diabetes

Diabetes Care in Scotland

DIRECT Study

Prevention in NHSGGC

Diabetes Research Update

Priorities of NHSGGC

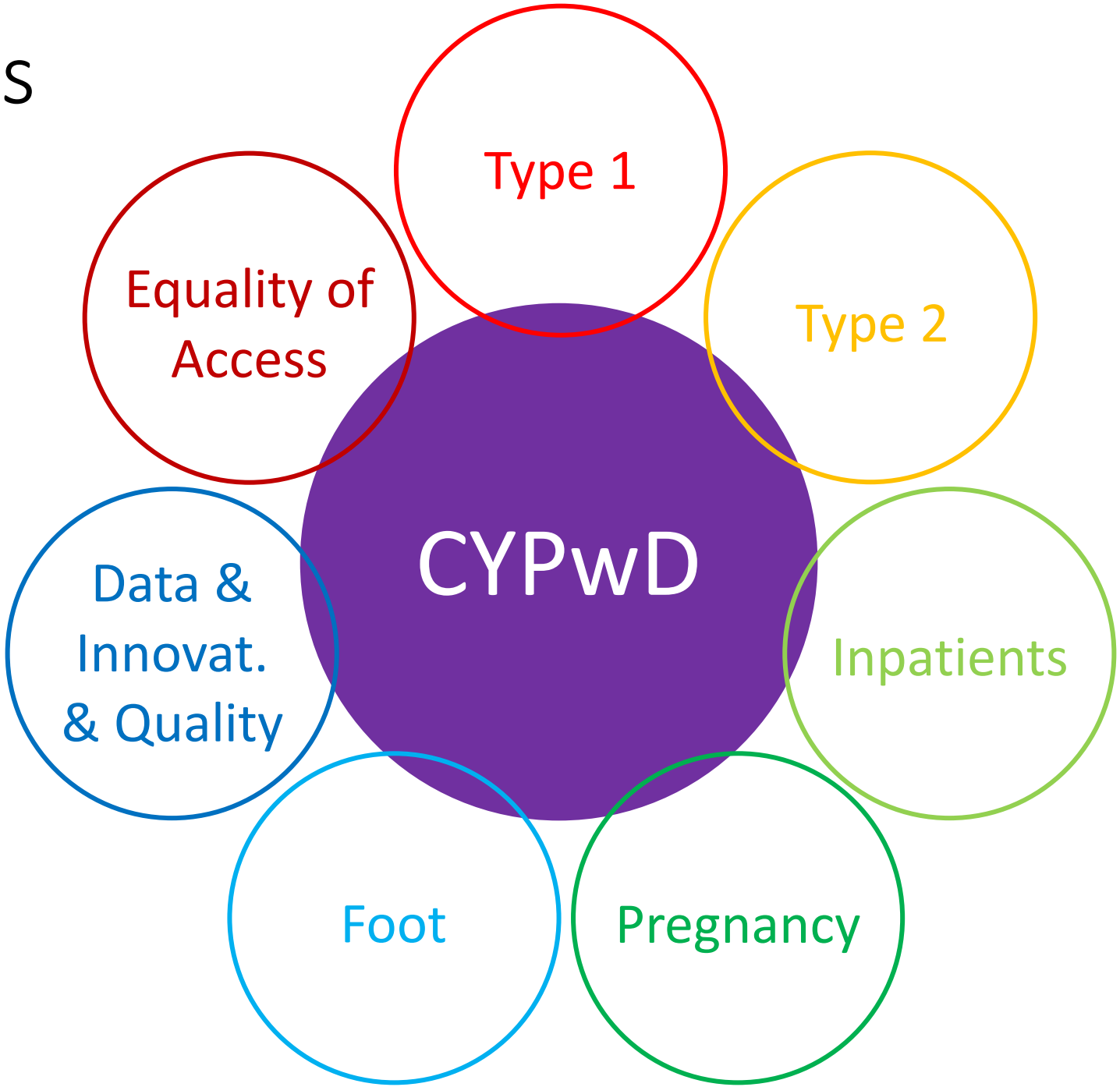
Subgroup Updates:

- Data, Innovations and Quality
- Equality of Access
- Foot
- Inpatients
- Pregnancy
- Type 1
- Type 2

Subgroup Updates:

- Data, Innovations and Quality
- Equality of Access
- Foot
- Inpatients
- Pregnancy
- Type 1
- Type 2

Diabetes MCN Groups



CYPwD MCN Committee membership

- Clinicians
  - Medical staff (Paediatric and Adult Diabetology)
  - Nurse Specialists
  - Dietitians
  - Clinical Psychologists
- Management
  - Operational managers
  - Central management
- Patient Representatives
  - Parents and Young people
  - Diabetes Scotland
- MCN Coordinator

CYPwD MCN Standing Agenda Items

1. Service (Staff, Facilities, OPC, IPs)
2. Service Interactions (Primary Care, Secondary Care)
3. Transition Process (Staff, Venues, Process of Care, Financing)
4. Technology (Devices, Monitoring, Data presentation & analysis)
5. Diabetes Education (Structured Education, Online & printed materials)
6. Education Facilities (Nurseries, Schools & Tertiary centres,)
7. Mental Health Care (Psychology, Psychiatry, CAMHS)
8. Social Services
9. Education Services

1. Service

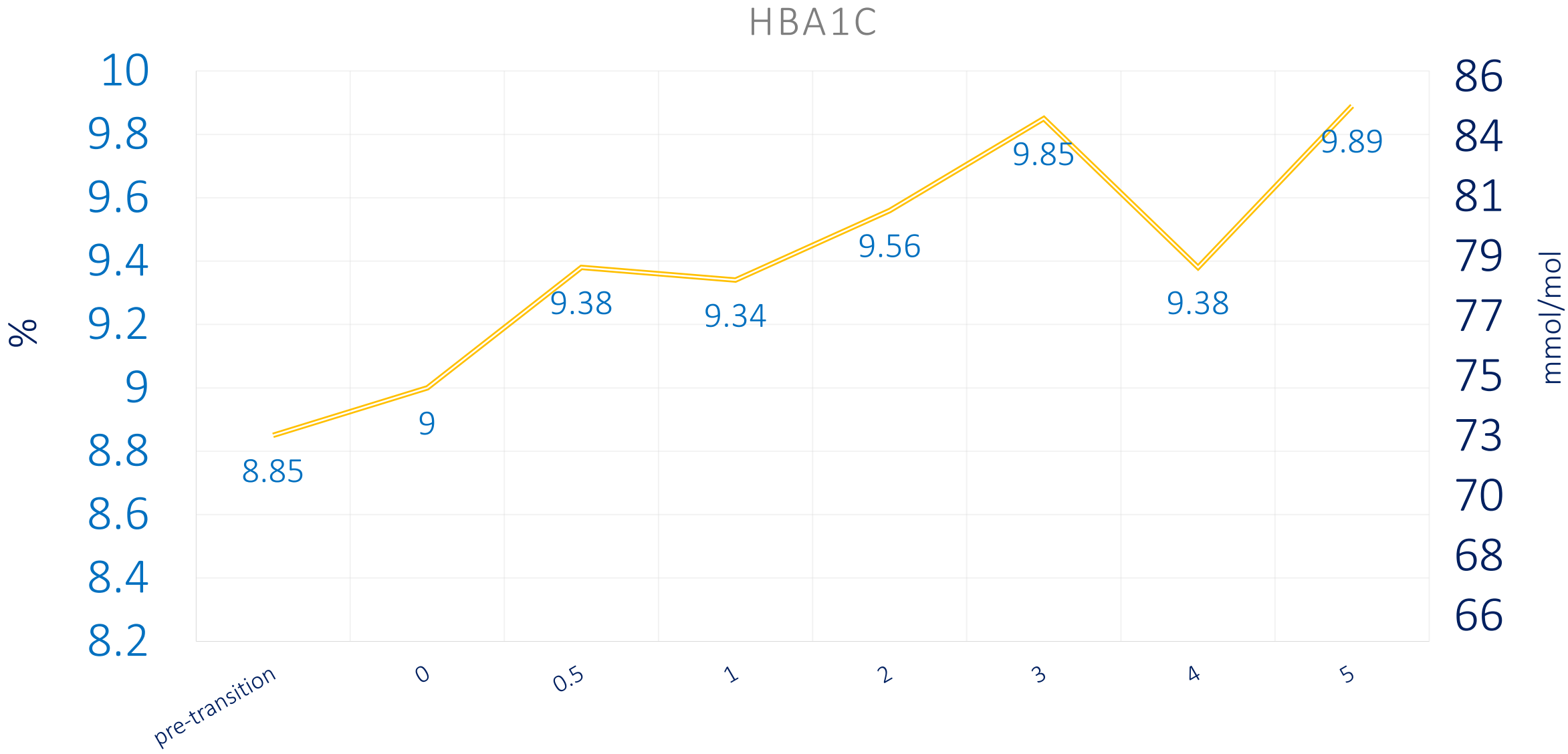
- Staff
- Venue
- Inpatient care
- Outpatient care
- Primary Care interaction
- Secondary Care interaction (Transition)

SGH Audit (2012): Transition Outcomes

- Despite a transition service in keeping with current guidelines, there is significant morbidity and mortality
  - Mortality 3.3% within 5 years of transition
  - Frequent and recurrent hospital admissions
  - High rates of retinopathy
  - 83.5% engagement with service

Laura McLaren, B. Kennon

Glycaemic control after Transition



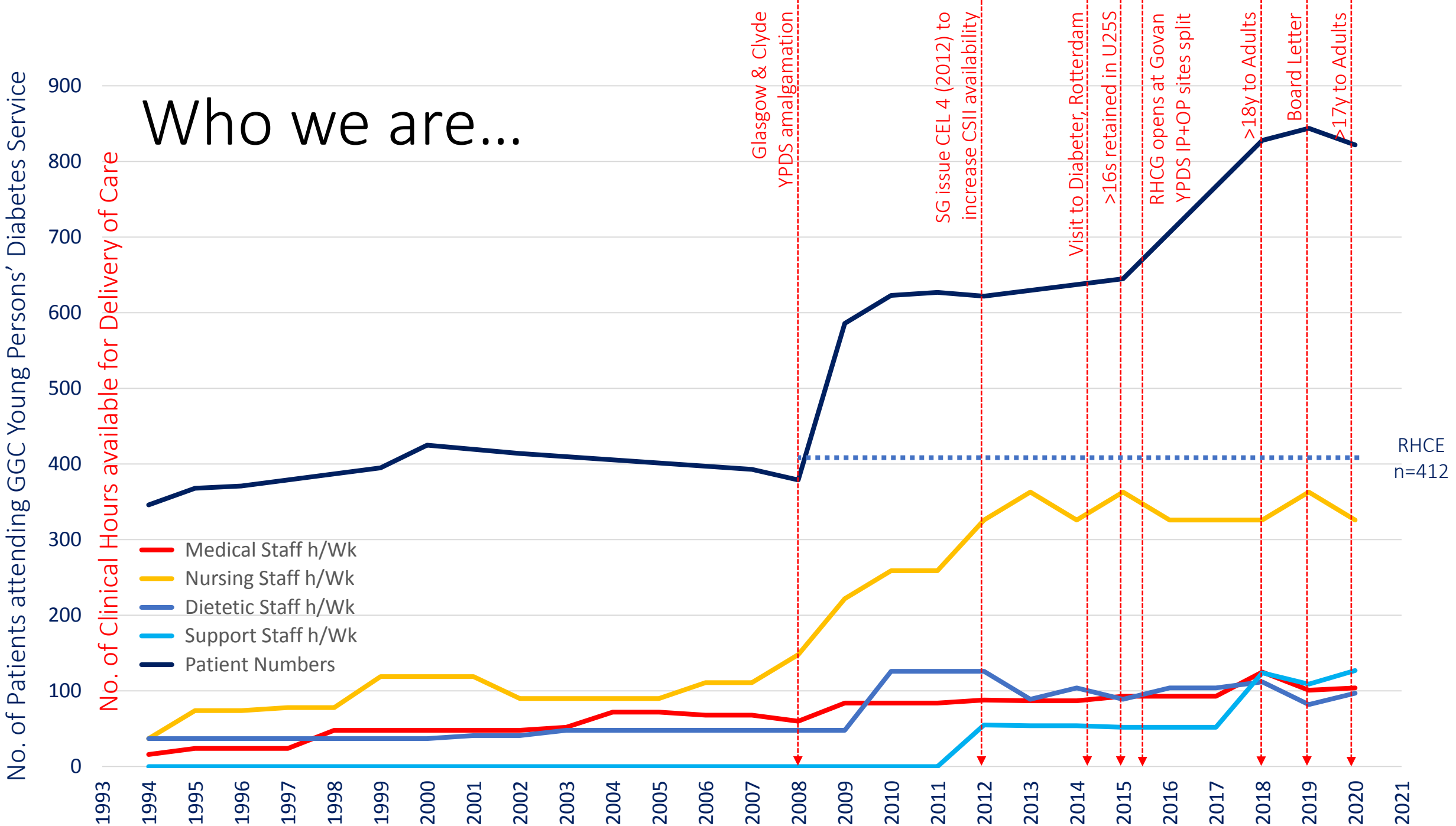
Service Development

- 2008 Integration of Greater Glasgow & Argyll & Clyde CDSs
- 2008 GGC CDS Plans for new hospital development submitted
- 2012 SG issues CEL-4 (2012) re Insulin pump provision
- 2012 CDS moves to Facility on Ward 6B, RHSCG (Yorkhill)
- 2012 Additional Nursing staff appointed to deliver pump care
- 2015 Board sponsored visit to Diabeter Care Centre, Rotterdam
- 2015 Report to GGC Board endorsed, agreeing to estab. U25S
- 2015 Retained patients in CDS (“U25S”)
- 2015 New RHCG opens on Govan site.
- 2015 U25S remains in 6B, Yorkhill, splitting IP and OP care
- 2018 920 patients up to 21 years of age seen in U25S …

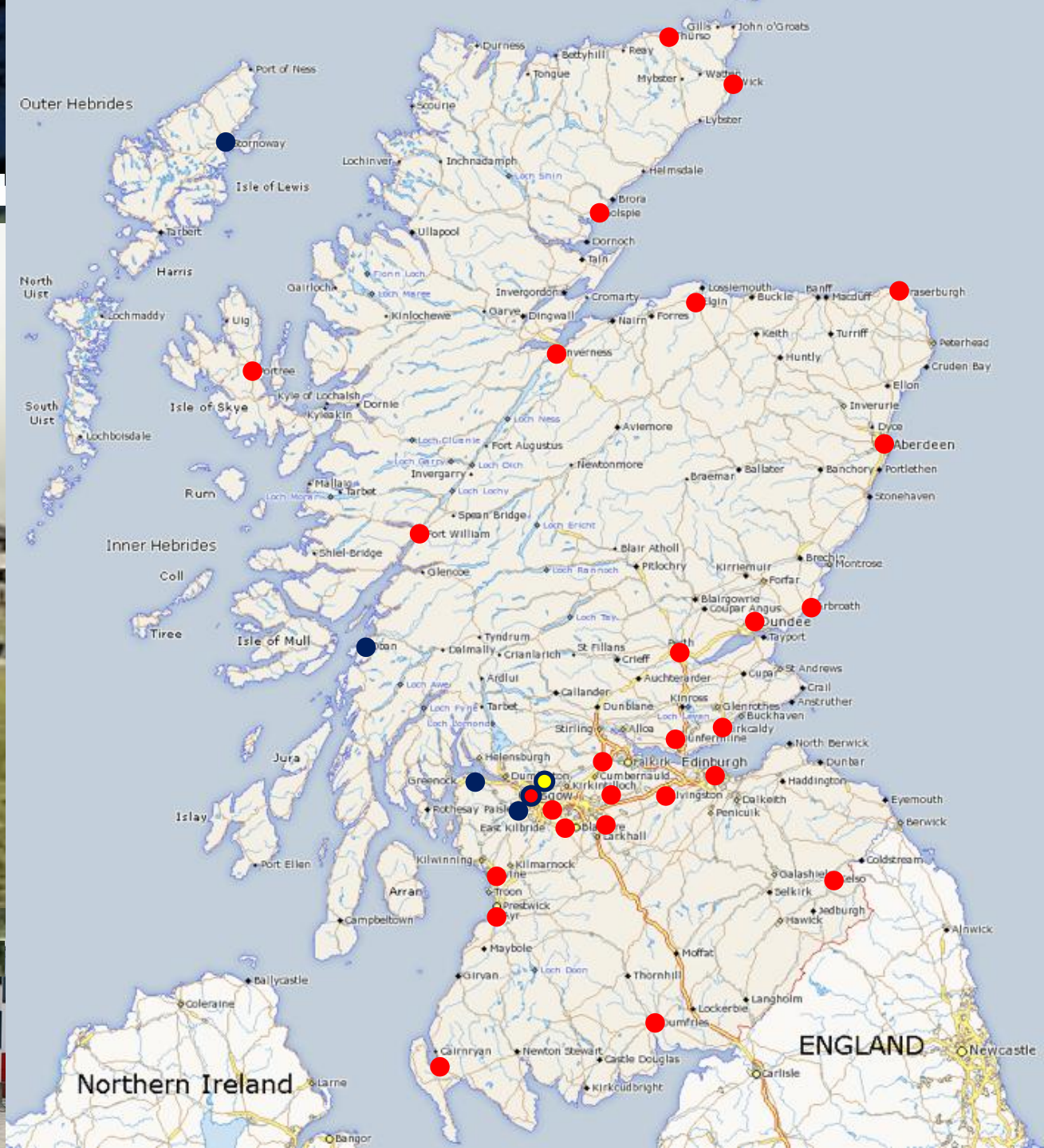
Age: 25 weeks *vs.*
25 months *vs.*
25 years

Diabeter,
Rotterdam, NL

Who we are…


No. of Patients attending GGC Young Persons' Diabetes Service
No. of Clinical Hours available for Delivery of Care
0
100
200
300
400
500
600
700
800
900
1993
1994
1995
1996
1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
2011
2012
2013
2014
2015
2016
2017
2018
2019
2020
2021
Glasgow & Clyde YPDS amalgamation
SG issue CEL 4 (2012) to increase CSII availability
Visit to Diabeter, Rotterdam
>16s retained in U25S
RHCG opens at Govan
YPDS IP+OP sites split
>18y to Adults
Board Letter
>17y to Adults
RHCE n=412
Medical Staff h/Wk
Nursing Staff h/Wk
Dietetic Staff h/Wk
Support Staff h/Wk
Patient Numbers

Where we are

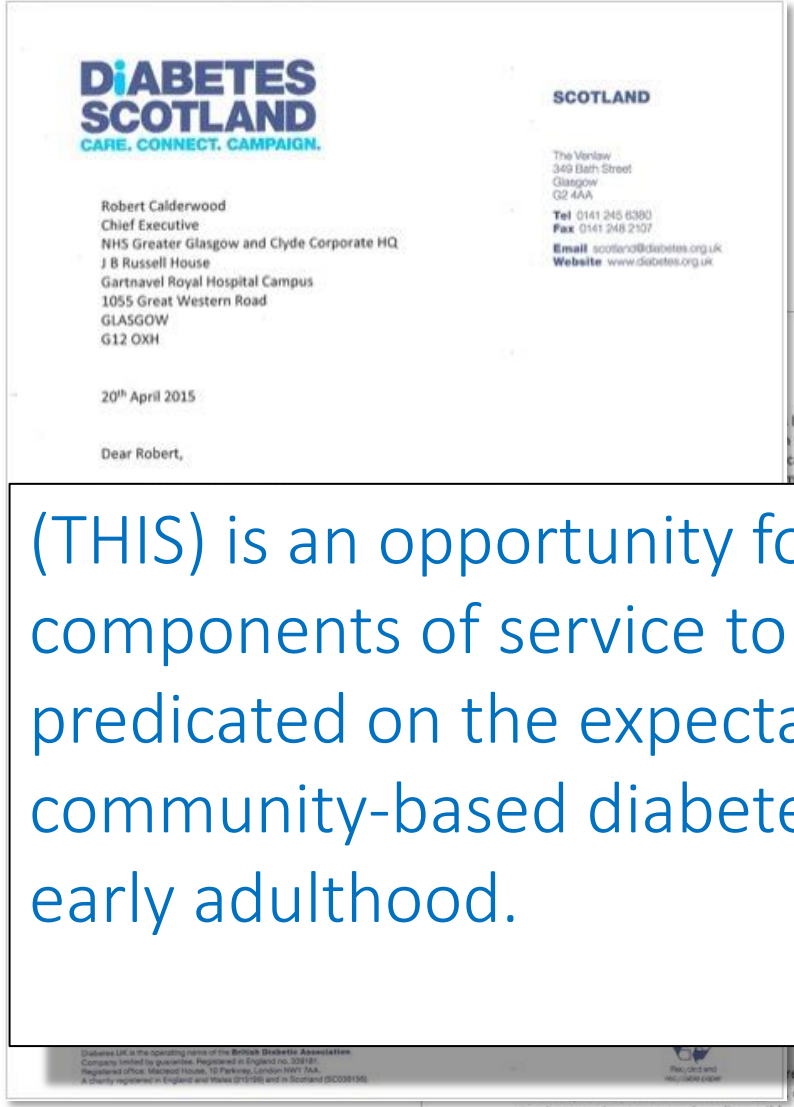


Outer Hebrides
Port of Ness
Stornoway
Isle of Lewis
Tarbert
Harris
North Uist
Lochmaddy
Uig
Portree
Isle of Skye
Kyle of Lochalsh
Kyleakin
Dornie
South Uist
Lochboisdale
Rum
Mallaig
Tarbet
Inner Hebrides
Shiel Bridge
Coll
Glencoe
Tiree
Isle of Mull
Oban
Jura
Islay
Port Ellen
Arran
Campbeltown
Ballycastle
Coleraine
Larne
Bangor
Northern Ireland
Gills
John o'Groats
Thurso
Durness
Bettyhill
Reay
Tongue
Mybster
Watten
Wick
Scourie
Lybster
Lochinver
Inchnadamph
Helmsdale
Brora
Golspie
Ullapool
Dornoch
Tain
Gairloch
Kinlochewe
Garve
Dingwall
Invergordon
Cromarty
Nairn
Forres
Lossiemouth
Elgin
Buckie
Banff
Macduff
Fraserburgh
Keith
Turriff
Peterhead
Huntly
Cruden Bay
Inverness
Ellon
Inverurie
Dyce
Aberdeen
Aviemore
Fort Augustus
Newtonmore
Braemar
Ballater
Banchory
Portlethen
Stonehaven
Invergarry
Spean Bridge
Fort William
Blair Atholl
Pitlochry
Kirriemuir
Brechin
Montrose
Forfar
Blairgowrie
Coupar Angus
Arbroath
Dundee
Tayport
Tyndrum
Dalmally
Crianlarich
St Fillans
Crieff
Perth
Auchterarder
Cupar
St Andrews
Crail
Anstruther
Ardlui
Callander
Dunblane
Kinross
Glenrothes
Buckhaven
Tarbet
Stirling
Alloa
Kirkcaldy
Dunfermline
North Berwick
Helensburgh
Oralkirk
Edinburgh
Dunbar
Greenock
Cumbernauld
Kirkintilloch
Haddington
Rothesay
Paisley
Glasgow
Dalkeith
Eyemouth
Penicuik
East Kilbride
Lanark
Berwick
Kilwinning
Kilmarnock
Coldstream
Galashiels
Kelso
Troon
Selkirk
Prestwick
Ayr
Jedburgh
Hawick
Alnwick
Maybole
Moffat
Girvan
Thornhill
Langholm
Lockerbie
Dumfries
Cairnryan
Newton Stewart
Castle Douglas
Kirkcudbright
Carlisle
ENGLAND
Newcastle

CDS & U25S History: *April 2015*

(THIS) is an opportunity for the current outpatient and education components of service to be retained on the Yorkhill site …
predicated on the expectation that the end point is a new and combined community-based diabetes centre for children and young people into early adulthood.

Robert Calderwood (NHS GGC CEO), April 2015


DIABETES SCOTLAND
CARE. CONNECT. CAMPAIGN.

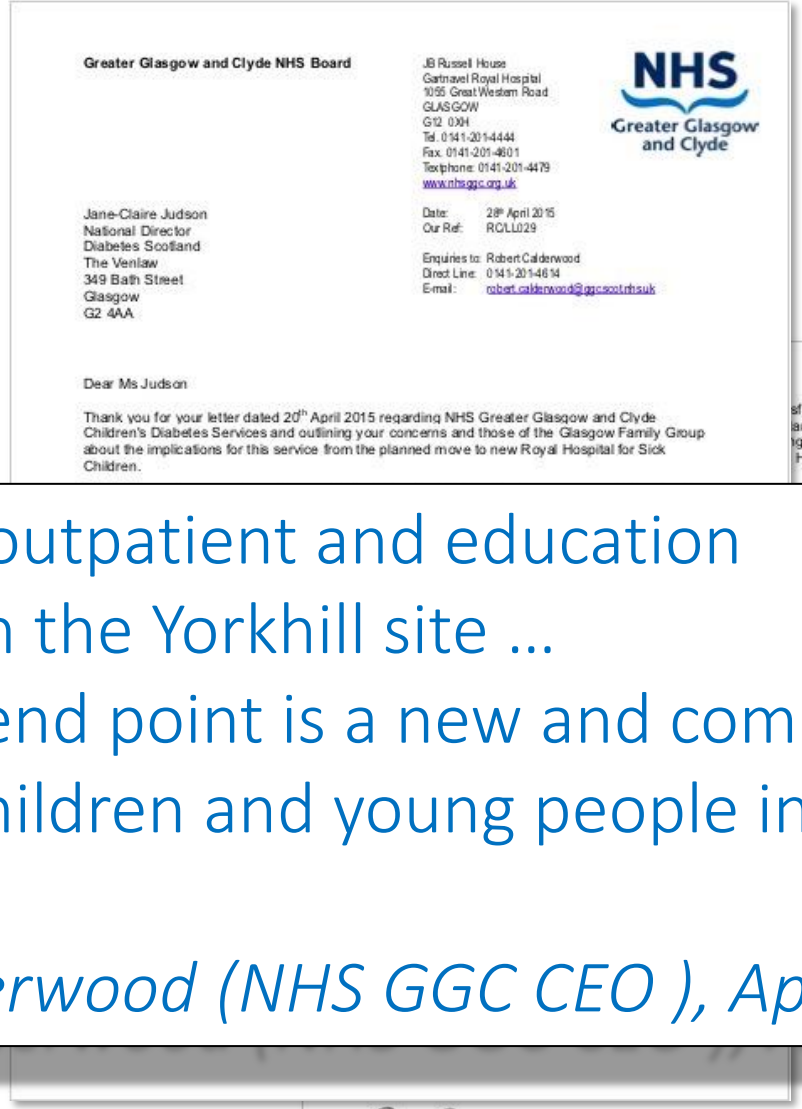
SCOTLAND

The Venlaw
349 Bath Street
Glasgow
G2 4AA
Tel 0141 245 6380
Fax 0141 248 2107
Email scotland@diabetes.org.uk
Website www.diabetes.org.uk

Robert Calderwood
Chief Executive
NHS Greater Glasgow and Clyde Corporate HQ
J B Russell House
Gartnavel Royal Hospital Campus
1055 Great Western Road
GLASGOW
G12 OXH

20th April 2015

Dear Robert,


Greater Glasgow and Clyde NHS Board

JB Russell House
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12 0XH
Tel. 0141-201-4444
Fax. 0141-201-4601
Textphone: 0141-201-4479
www.nhsggc.org.uk

NHS Greater Glasgow and Clyde

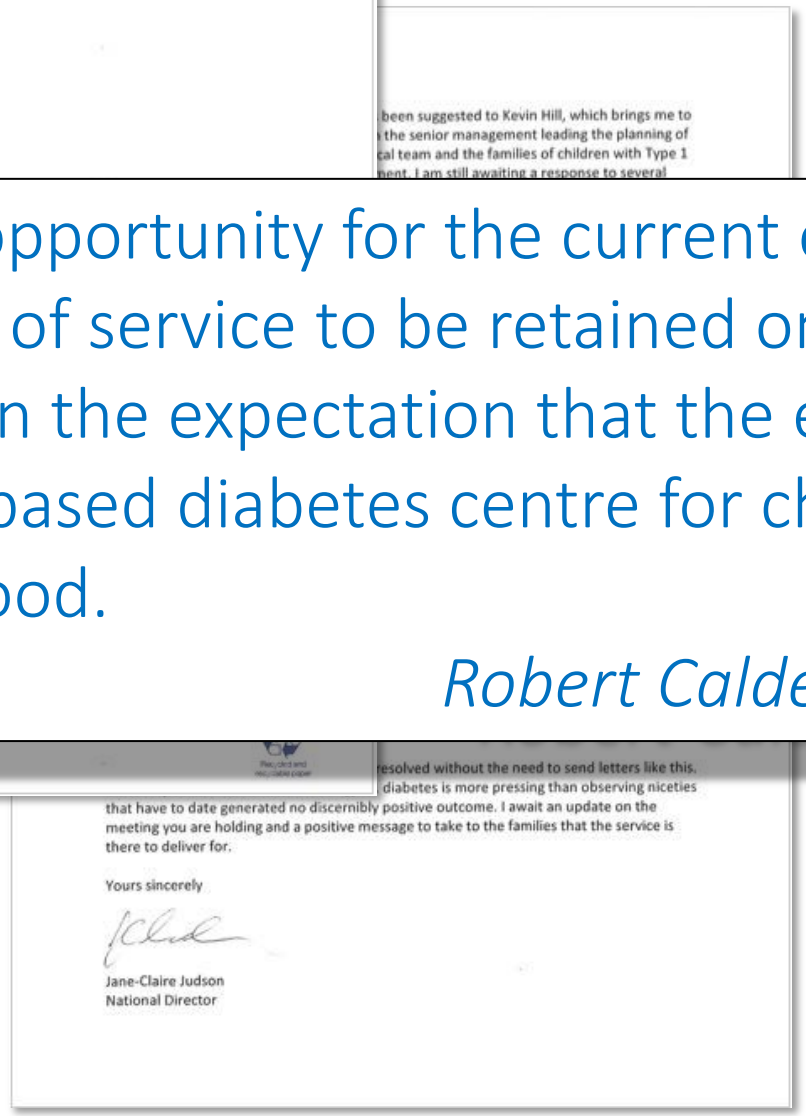
Jane-Claire Judson
National Director
Diabetes Scotland
The Venlaw
349 Bath Street
Glasgow
G2 4AA

Date: 28th April 2015
Our Ref: RC/LL029

Enquiries to: Robert Calderwood
Direct Line: 0141-201-4614
E-mail: robert.calderwood@ggcscotnhs.uk

Dear Ms Judson

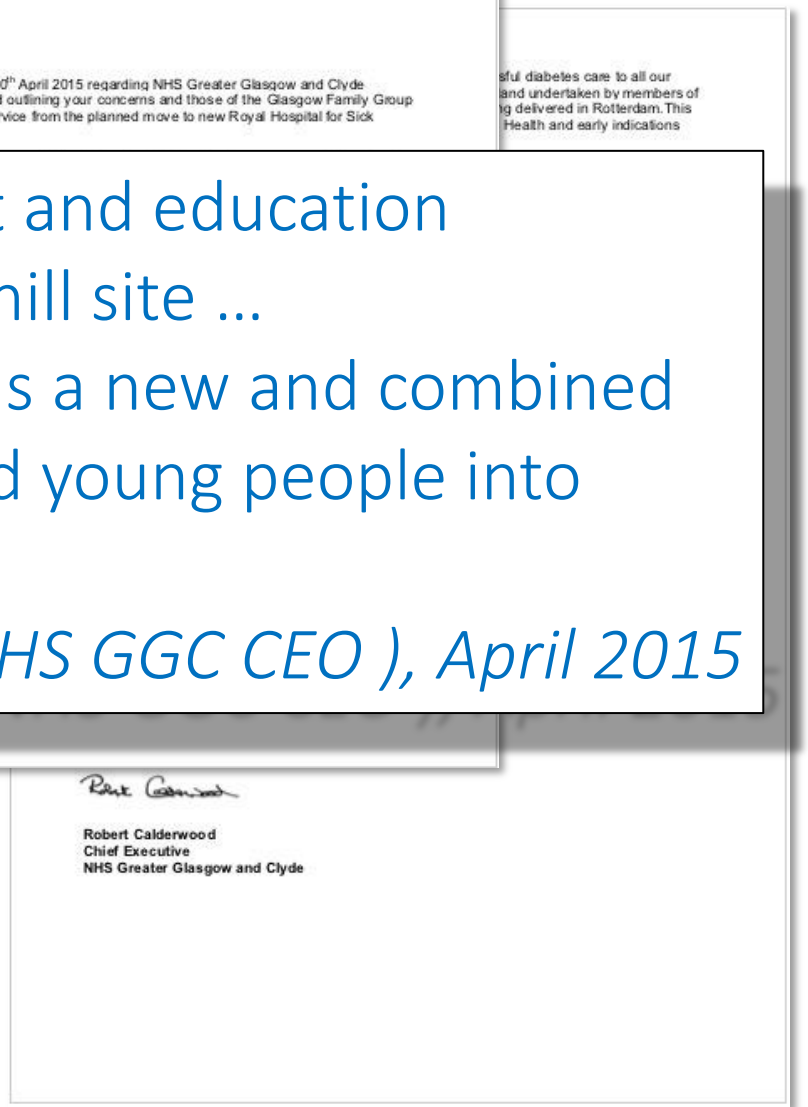
Thank you for your letter dated 20th April 2015 regarding NHS Greater Glasgow and Clyde Children's Diabetes Services and outlining your concerns and those of the Glasgow Family Group about the implications for this service from the planned move to new Royal Hospital for Sick Children.


been suggested to Kevin Hill, which brings me to
the senior management leading the planning of
cal team and the families of children with Type 1
nent. I am still awaiting a response to several

resolved without the need to send letters like this.
diabetes is more pressing than observing niceties
that have to date generated no discernibly positive outcome. I await an update on the meeting you are holding and a positive message to take to the families that the service is there to deliver for.

Yours sincerely

Jane-Claire Judson
National Director


sful diabetes care to all our
and undertaken by members of
g delivered in Rotterdam. This
Health and early indications

Robert Calderwood
Chief Executive
NHS Greater Glasgow and Clyde

DRAFT REPORT ON DIAB

Dear Coral,

It appears you may not have rece
new children's hospital. The answ
details included in our original rep
surprised to see that the many ex
our original report as an attachme

Unfortunately, we were not reque
Despite this, we drafted the attach
expansion requirements, and the
"Output Based Specification" docu
point so we can attempt to fulfill y

We suspect our situation is not un
report on service needs for the ne
absolute priority. We hope our exp
adequate consultation.

Yours sincerely,

Yorkhill Diabetes Service

DIAB SERV 20180510 GGC

As with other Services that
Service is principally an ou
needed. The clinical pressu
some years, due to several

- The growing comp
  treatment, and the
- Steady rise in patie
  for treating Type 1
- Geographical sepa
  Hospital for Childr
  on the northern Yo
- Retention of patie
  transferred aged 1

Despite such increasing bu

- No concomitant in
- No progress in dev
- No increased adult
- No decision on the
  site in less than 12
- No replacement of

There is now a great need

These issues have been dis
relocation, since 2008, wh
Diabetes Service within the
additional pressures, witho
on nursing and dietetic col
staff clinics).

The Children's Diabetes Se
change. In recognition of t
Diabetes Service, and in an
integration, and Under 25
Diabetes Service staff have
change have been made re
change dramatically, includ

Current patient numbers a
last 5 years. There have be
although there was a locur
Robertson will retire in Sep
considering succession pla

Proposals for Service Deve

If current patient numbers
staffing numbers are adeq

!
!
!
Ms.!Jane!Grant!
Chief!Executive!Officer!
Greater!Glasgow!and!Cly
NHS!Greater!Glasgow!an
J!B!Russell!House!
Gartnavel!Royal!Hospital
1055!Great!Western!Roa
GLASGOW!
G12!0XH!
!
!
21!January!2019!
!
!
Dear!Ms.!Grant,!
!
I!write!seeking!clarity!re!
Service!in!general,!and!t
!
Diabetes!patients!defaul
return!some!years!later!
concern.!In!a!condition!c
within!a!clinical!service!c
However,!we!all!appreci
shortened!by!serious!phy
psychological!burdens!of
condition.!
!
I!will!not!reiterate!the!hi
(U25S),!suffice!to!say!it!f
the!Netherlands,!and!a!s
Diabetes!Service!along!si
adult!services!and!provis
withheld!transfer!of!pati
continue!to!attend!Yorkh
most!importantly,!to!dev
mental!health!support!fo
!
Since!2015!the!process!o
Yorkhill!site.!Adult!nurse
bringing!their!expertise,!
further!integration!has!s
largely!that;!a!concept.!I
coordinated!by!a!single!c

DIAB SERV 2019040

Outline

It is now one month since
Management representati
these issues included:

1. Proposed patient a
2. Medical staffing nu
3. Department locatic
4. Peripheral clinic pr

We propose to increase CD

1. Increased CDS sess
   Paediatric hybrid p
   Paediatrics appoint
2. Appointment of a S
3. Review of further C
   additional staff ma

Proposed Patient Age Ra

For 4 years the Children's
Care Hospital site, rather t
"Under 25 Service". Over t

Patient retention on one s
from the five adult centres
had to absorb ever-increas
This has imposed an intole
resourced department, res
multiple sites across Glasg

Due to this staffing imbala
and over to separate GGC
well as those over 18 years
taken lightly, and is in man
the current staffing situati

Our service must continue
for the service's number o
years, depending on Mr. H
Medical Directorate. This v
potentially requiring adult
appointments.

DIAB SERV 20190414

Executive Summary

The GGC Children's Diabetes
significant inpatient respons
do all other hospital- and co
standard of diabetes care ha
"temporary" facilities of Wa

4 years after every other dep
remains in a building slated
facilities, the CDS now faces
to date, no involvement of C

Over the last 10-15 years the
technologies. Purpose-built
providing best possible care
Imaging, and Emergency De
needed to provide the care
requirements, but these hav

The aims of any modern serv
has seen such enormous inn

1. Inpatient care – at di
   well as regular reviev
2. Outpatient care – to
   quality of life, and to
3. Education – to empo
   optimise the use and

In April 2015, prior to the m
Chief Executive, Mr. Robert
the plans of the new hospita
Director of Diabetes Scotlan
and education components
predicated on the expectatic
centre *for children and youn*

The GWACH is now schedule
accommodation, and is now
patients, their families and s
proposed many years ago ar
Chief Executive. The facilitie
in the document below.

NHS Greater Glasgow and Clyde	Paedia
FROM	Ian Craig
TO	Jamie Re
DATE	01/03/20
Subject	Chronica Long-ter
Situation	Long-ter a life-lon inadequa 1. F 2. D 3. F 4. L Lack of cl straining
Background	General • Over expe • Clinic Cont incre witho • CDS care inclu new • Long deve incor • GGC c c c • Engli non- simil • Mini curre • Curre • Curre on 8 • Curre work • In ad Diab provi year, to a

Ms. Jane Grant
Chief Executive Officer
Greater Glasgow and Clyde NHS Board
NHS Greater Glasgow and Clyde Corporate HQ
J B Russell House
Gartnavel Royal Hospital Campus
1055 Great Western Road
GLASGOW
G12 0XH

1 November 2019

Dear Ms. Grant,

You may recall my letter to you of 21 January, 2019, s
regard to the Children's Diabetes Service (CDS), and th
service. Although I am not aware of having received a
that must cross your desk daily. Of course, many of th
colleagues, and they will take forward the Board's pla

It is now over 9 months since my letter and, unfortuna
intentions. I previously outlined the reasons for and o
and how this concept was strongly supported by patie
Board itself. However, by its very nature, the concept
paediatric and adult services, and so for this reason I s

Along with paediatric colleagues in other services, we
within a defined age range. This used to be up to the a
move to the new Govan site. At that time, however, th
the lead up to this move, the concept of the "Under 2
attending the CDS had their care retained, so that you
each of the three GGC outpatients' sites of the CDS; th
(GWACH), Royal Alexandra Hospital (RAH), Paisley, an

Throughout, we have enjoyed excellent and enthusias
would all acknowledge that such support has been lim
dietitian would attend one clinic per week across the
expanded from 480 patient under 15 years 5 years ag
Under 25s Service. We currently care for 840 patients

2. Service Interactions

- Primary Care
  - Referral & Support
  - Type 1 Awareness
- Secondary Care
  - External Service Provision
    - Highlands
    - Western Isles
  - Transition
  - MCN Subgroups
    - T1DM - Autoantibodies, CGM
    - Inpatients - Electronic Prescription
- Tertiary Care
  - One of 2 National Tertiary Care centres
    - Critical Care Retrieval

Think! Test! Telephone!

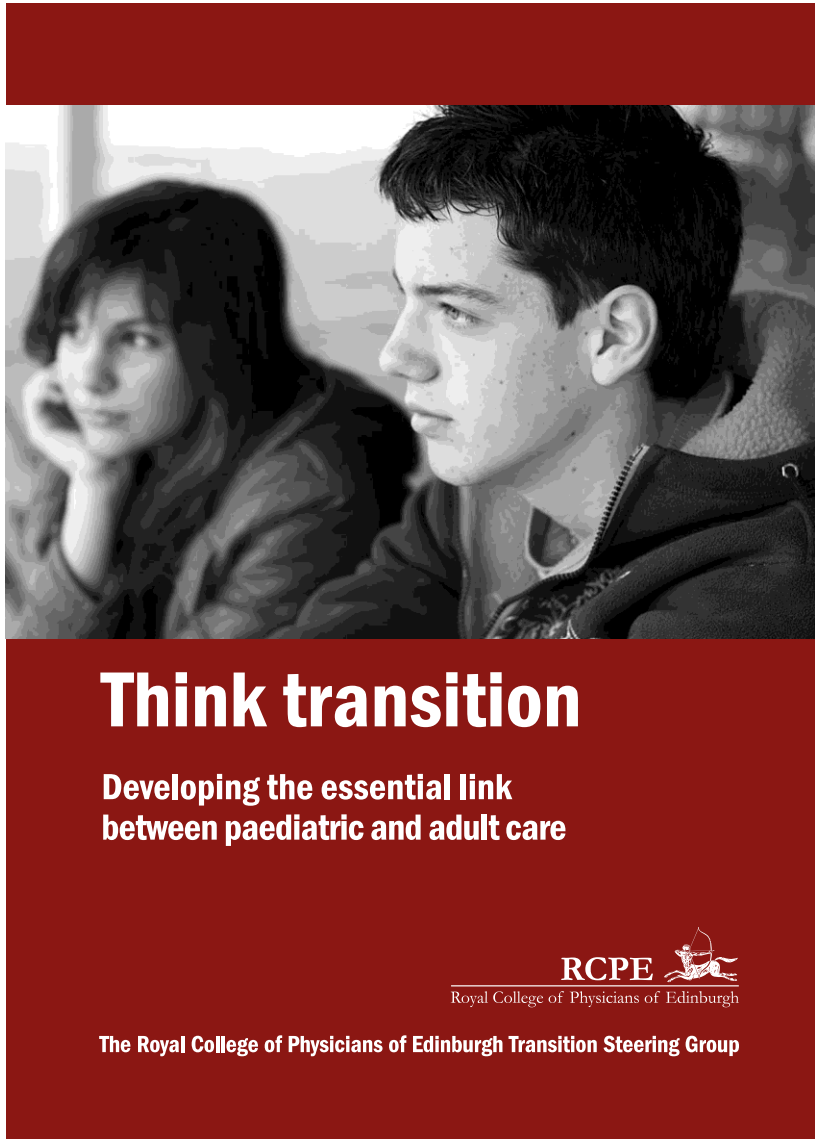
- Think!
  - Thirsty
  - Tired
  - Thin
  - Toileting
- Test!
  - Cap BG
  - NO HbA1c!
  - NO GTT!
- Telephone!
  - Immediately

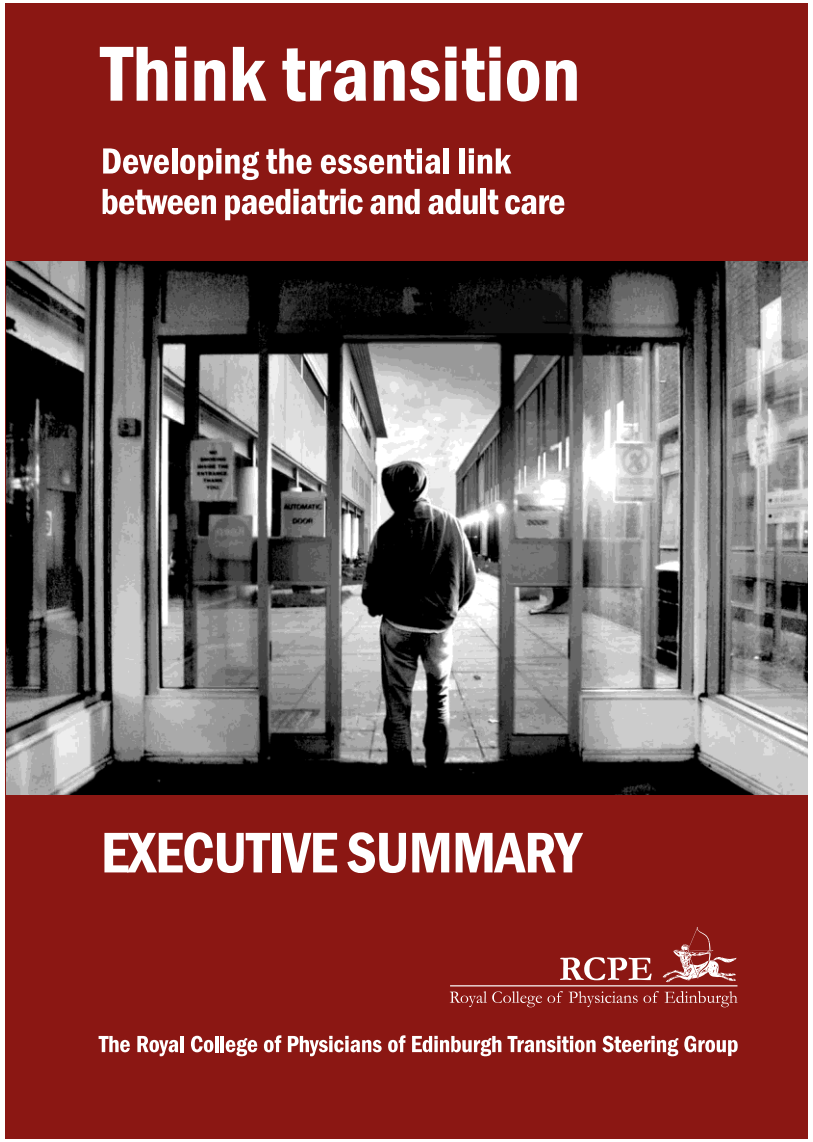
GGC Referral Guidelines available online

3. Transition Process

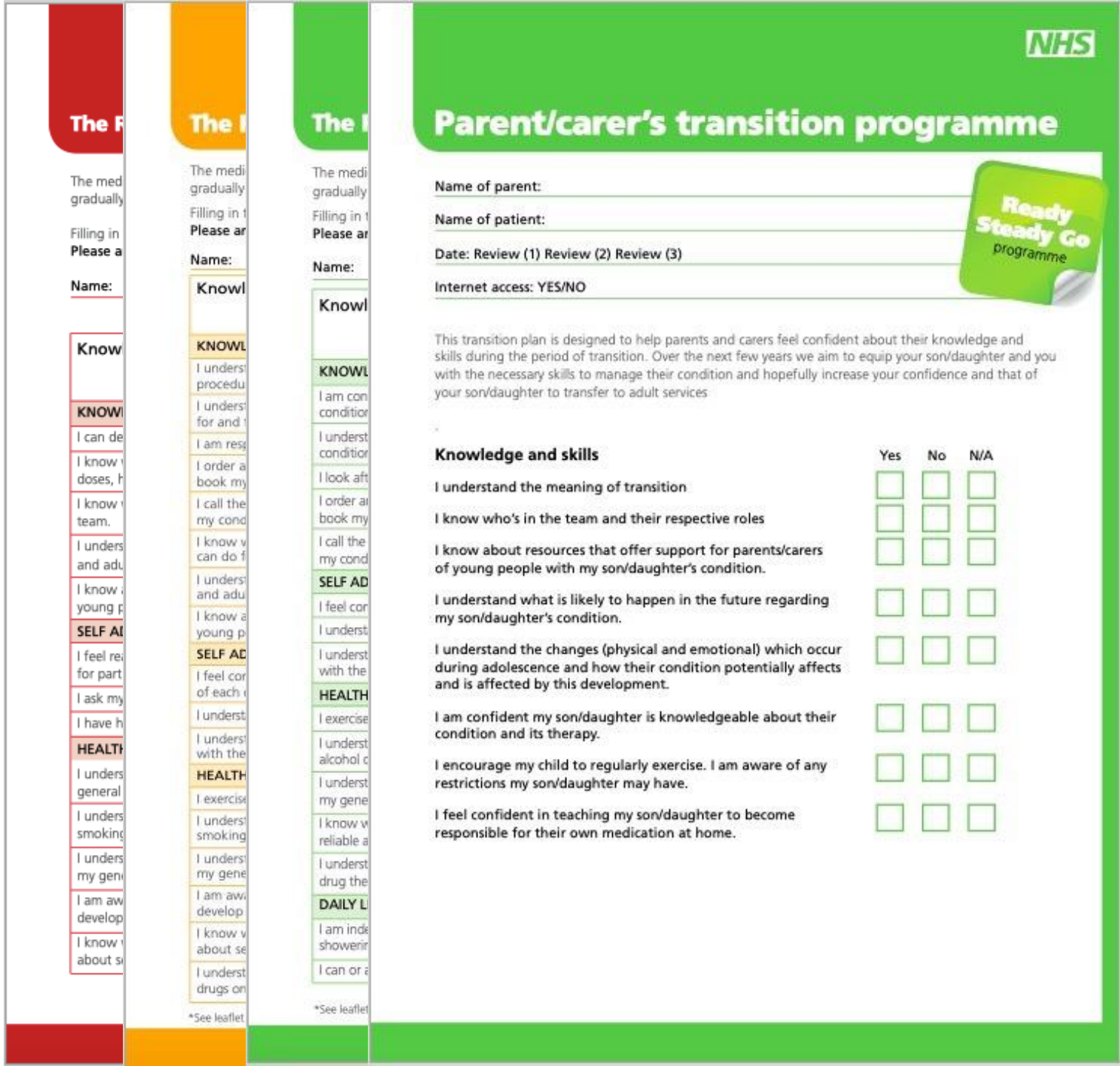
- Multi-centre vs. Single centre
- Bring Service to the Patient
  - Rather than send Patient to the Service
- Aim to retain young people in care
  - Prevent deaths
  - Prevent returning late with established complications
- Young Adult Diabetes Nurse
- Develop relationships
- Ready, Steady, Go Programme
- House of Care Programme

Think Transition





Ready, Steady, Go



4. Technology

- FGM
- CGM
- CSII
- Data
  - LibreView
  - Dexcom Clarity
  - Diasend
  - CareLink
- Maintaining currency
- Data overload
- Patient interaction
  - Email, telephone, etc.

Technology measures (SCI Diabetes)

	GGC	Scotland
• FGM	45.3 %	41.8 %
• CSII	33.3 %	37.8 %
• CSII with HbA1c > 75	7 %	11.1 %
• CGM	7.1 %	7.6 %

5. Diabetes Education

- Long history of Structured Education
  - Carb Counting from Day 1
  - Continual training
  - Involvement of all family
- Individual training
- Family training
- Group training
- Carer training

6. Education Facilities

- Service venue
- Printed materials
- Online services
  - App
  - Website

7. Other Services

- Mental Health Care
  - Clinical Psychology provision
    - Under 16 y
    - Over 16 y
  - Psychiatry
    - Liaison Psychiatry
    - CAMHS
- Education Services
  - GGC
  - Other Councils
  - National
- Social Services

Service parameters *(SCI Diabetes Dashboard)*

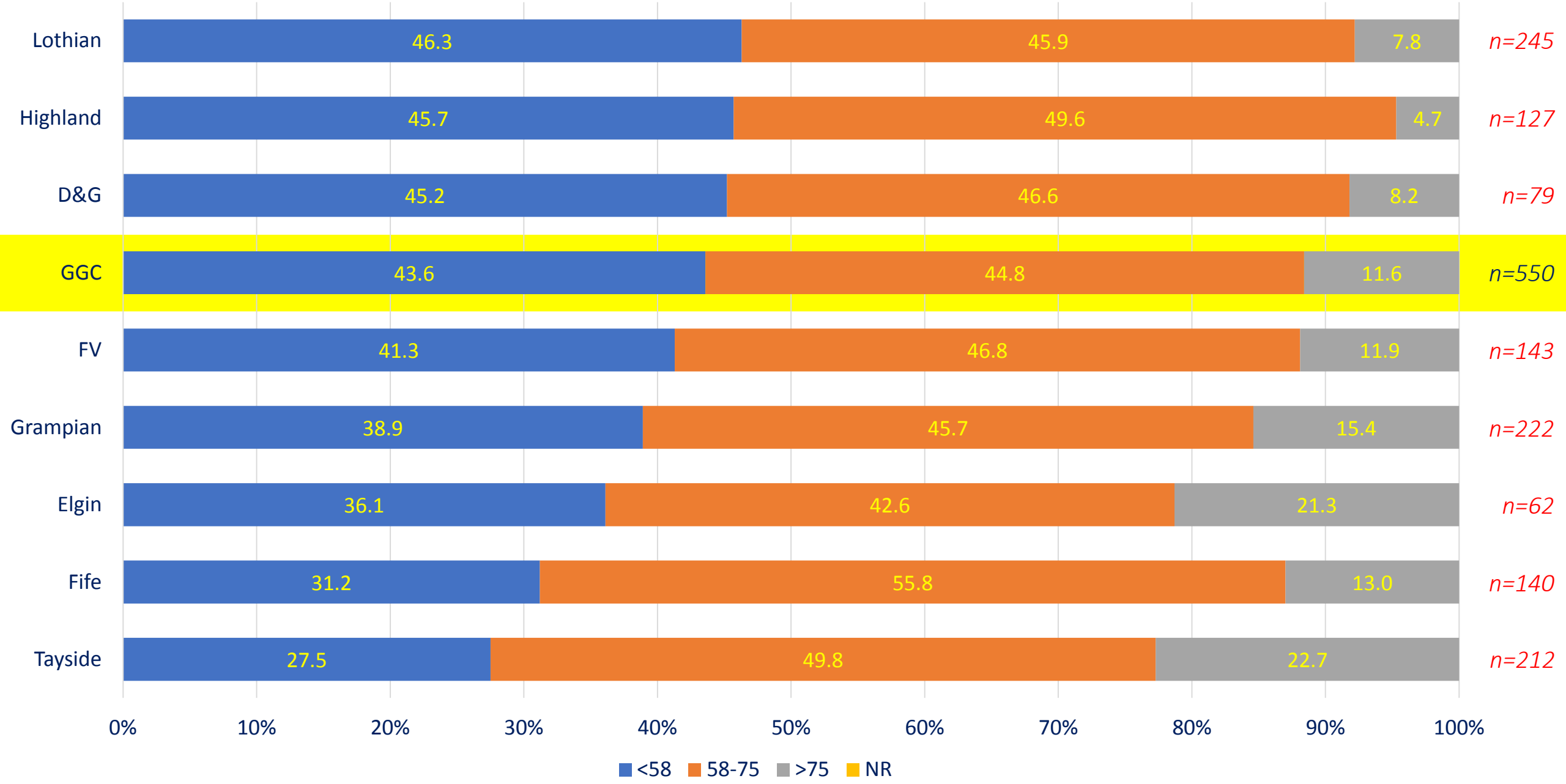
	GGC	Scotland
• HbA1c		
• Median HbA1c	62 mmol/mol	63 mmol/mol
• HbA1c < 48 < 12m post. Dx	11.6 %	17.0 %
• HbA1c < 58 mmol/mol	35.8 %	32.0 %
• HbA1c > 75 mmol/mol	18.2 %	20.5 %
• Ages		
• 0 - 4.99 y	3.8 %	4.3 %
• 5 - 11.99 y	36.4 %	34.3 %
• 12-17.99 y	59.8 %	61.5 %
• Sex		
• Female	51.6 %	48.8 %
• Male	48.4 %	51.2 %

SIMD Data & Service Challenges

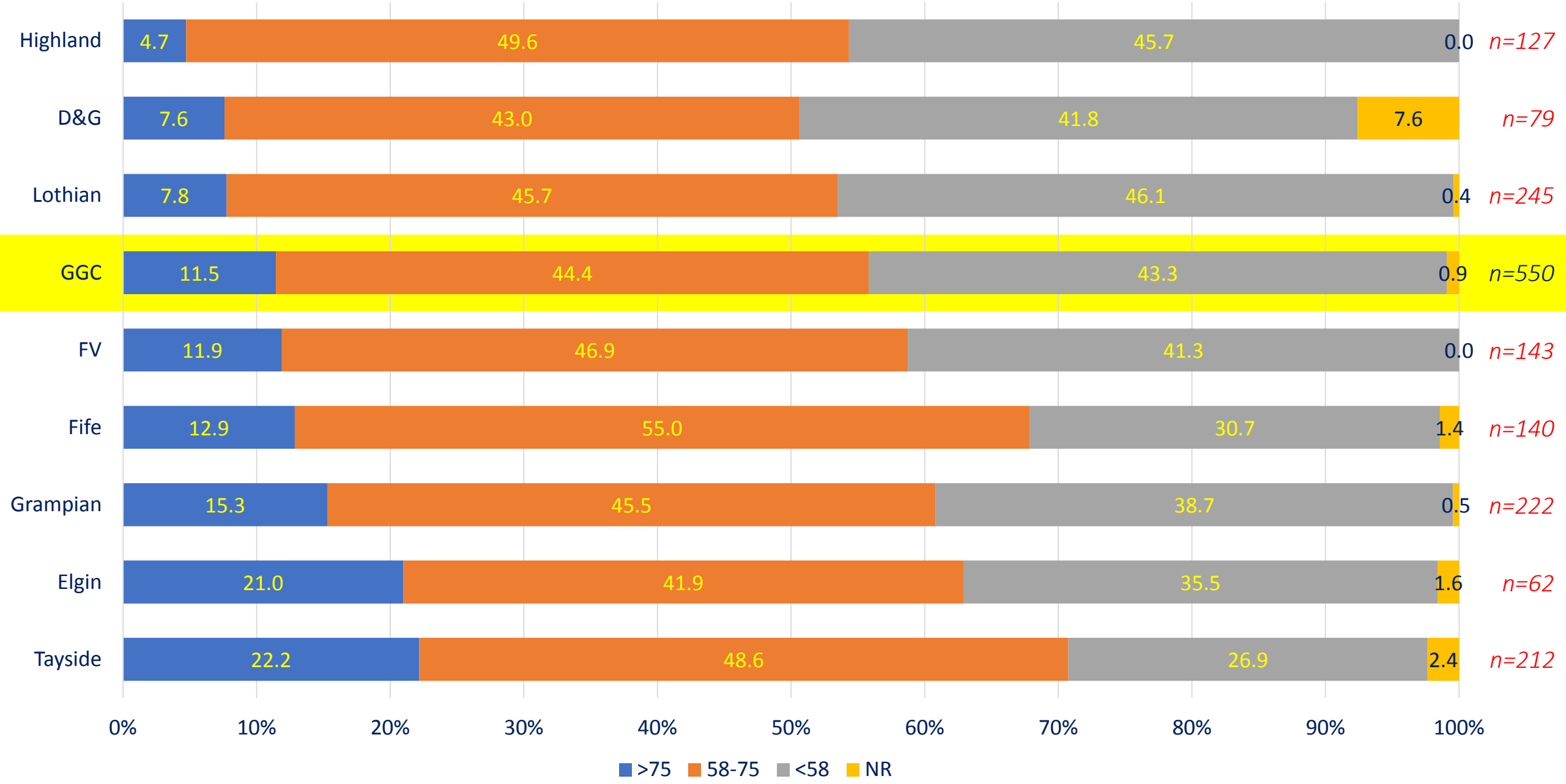
	GGC	Scotland
• SIMD 1	37.10 %	20.20 %
• SIMD 2	17.30 %	20.50 %
• SIMD 3	12.70 %	18.90 %
• SIMD 4	11.90 %	19.50 %
• SIMD 5	19.90 %	18.90 %

- Particular Challenges of Service delivery throughout GGC
  - Deprivation
  - Geographical area size and conformation
  - Multiple ethnicities and languages

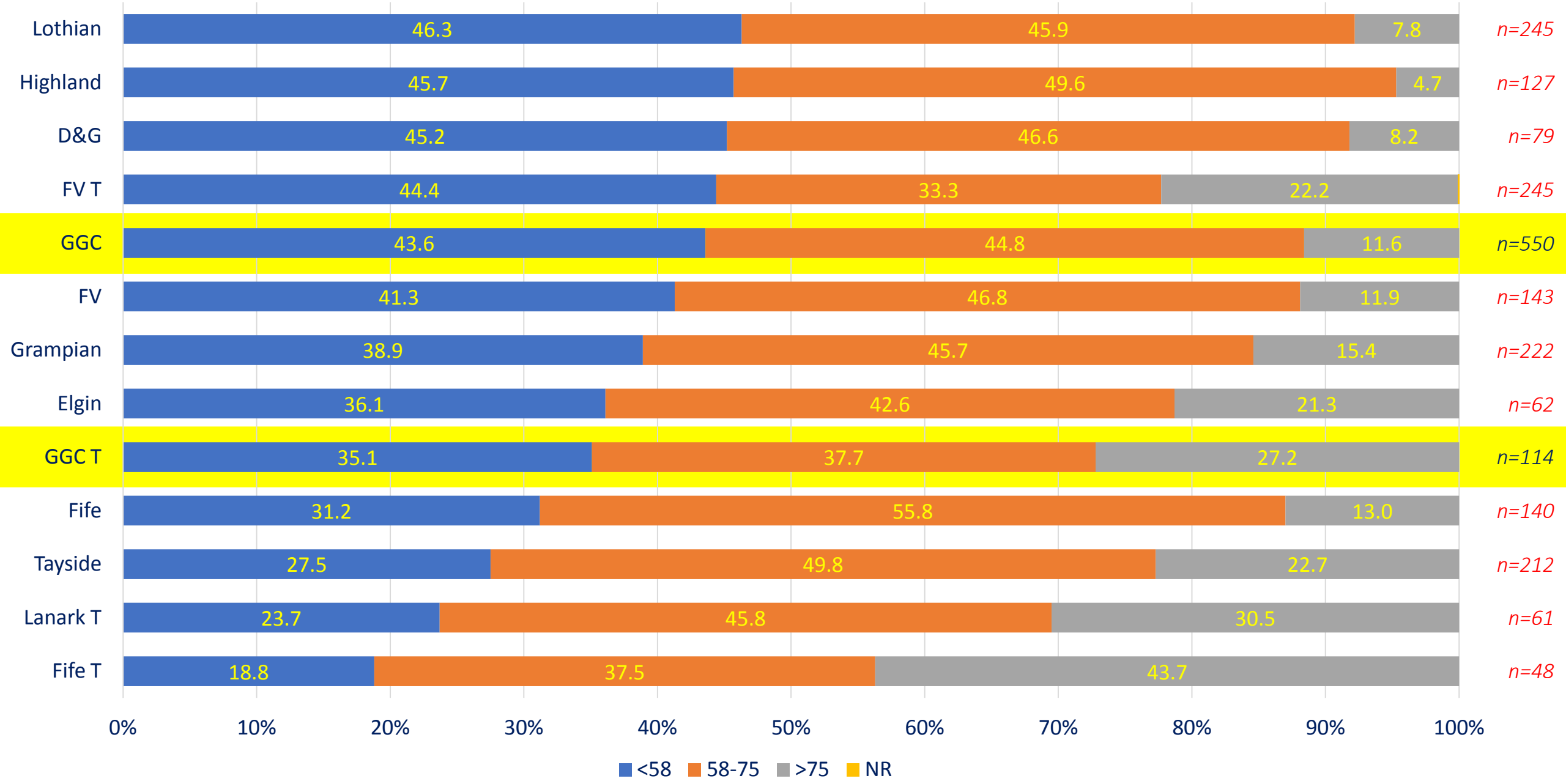
HbA1c 0-18 years: % < 58 mmol/mol (2018 Q4)



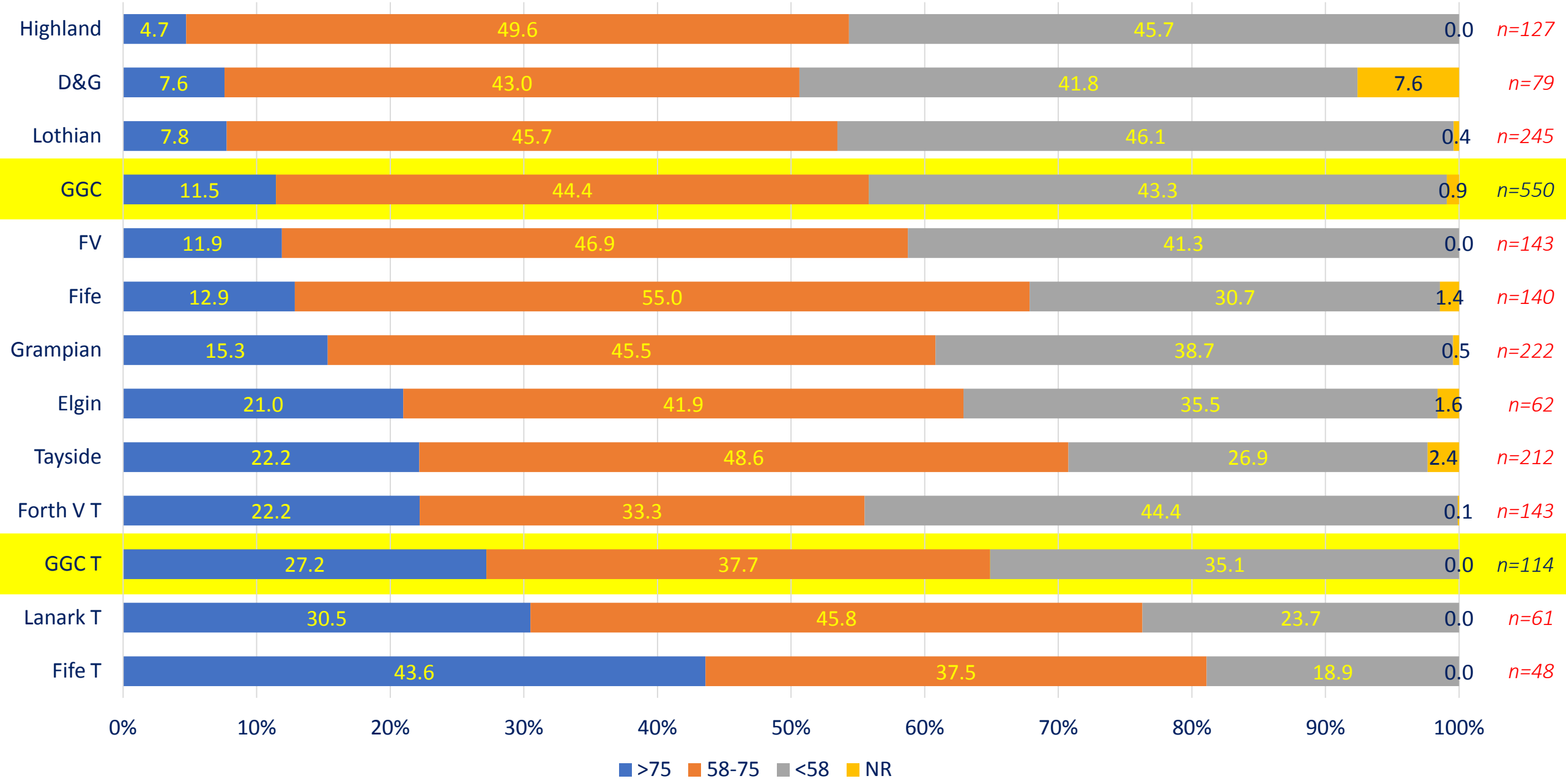
HbA1c 0-18 years: % > 75 mmol/mol (2018 Q4)



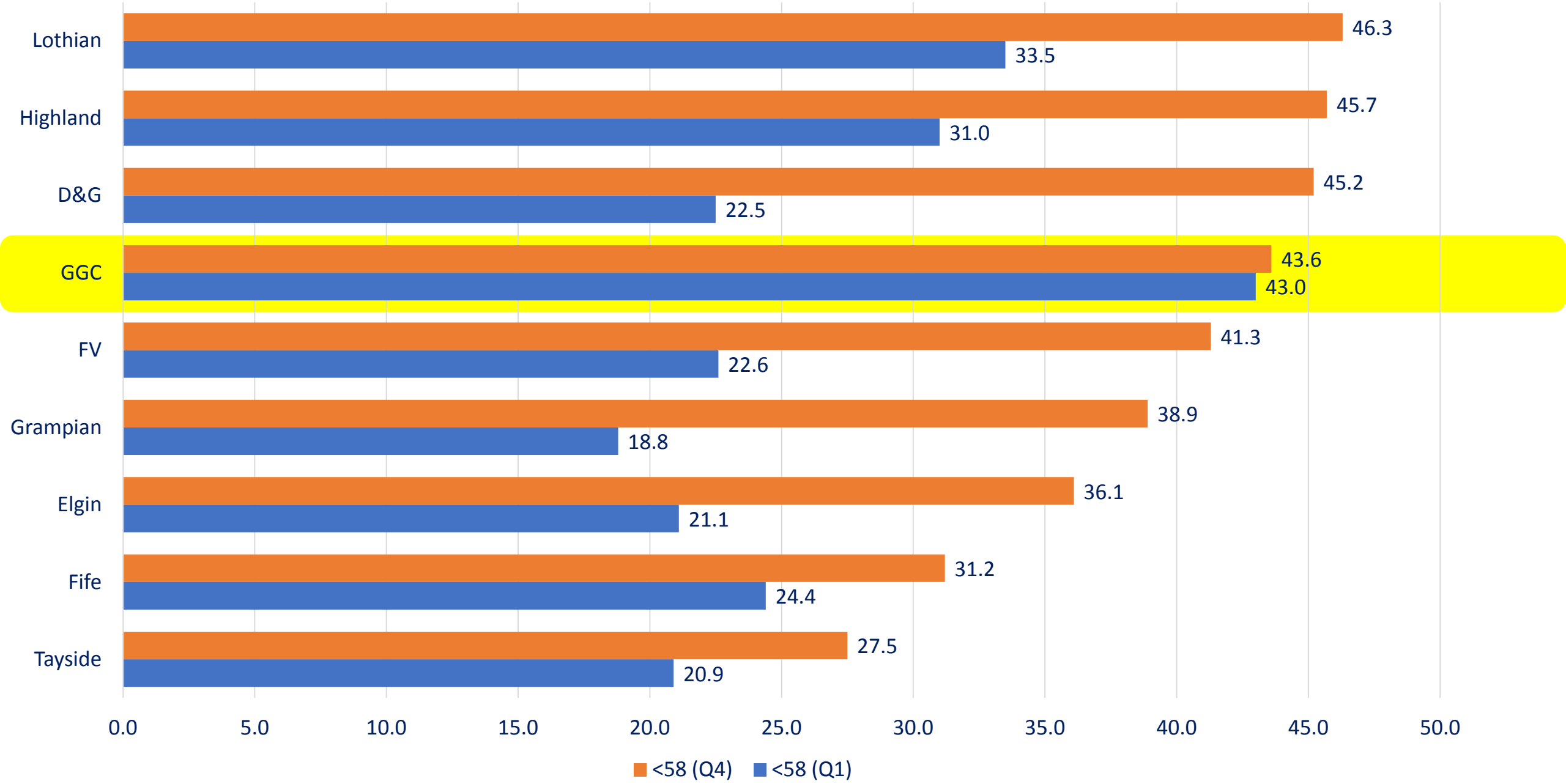
HbA1c 0-18 years: % < 58 mmol/mol (2018 Q4)



HbA1c 0-18 years: % > 75 mmol/mol (2018 Q4)



HbA1c 0-18 years: % < 58 mmol/mol (2018 Q1&4)

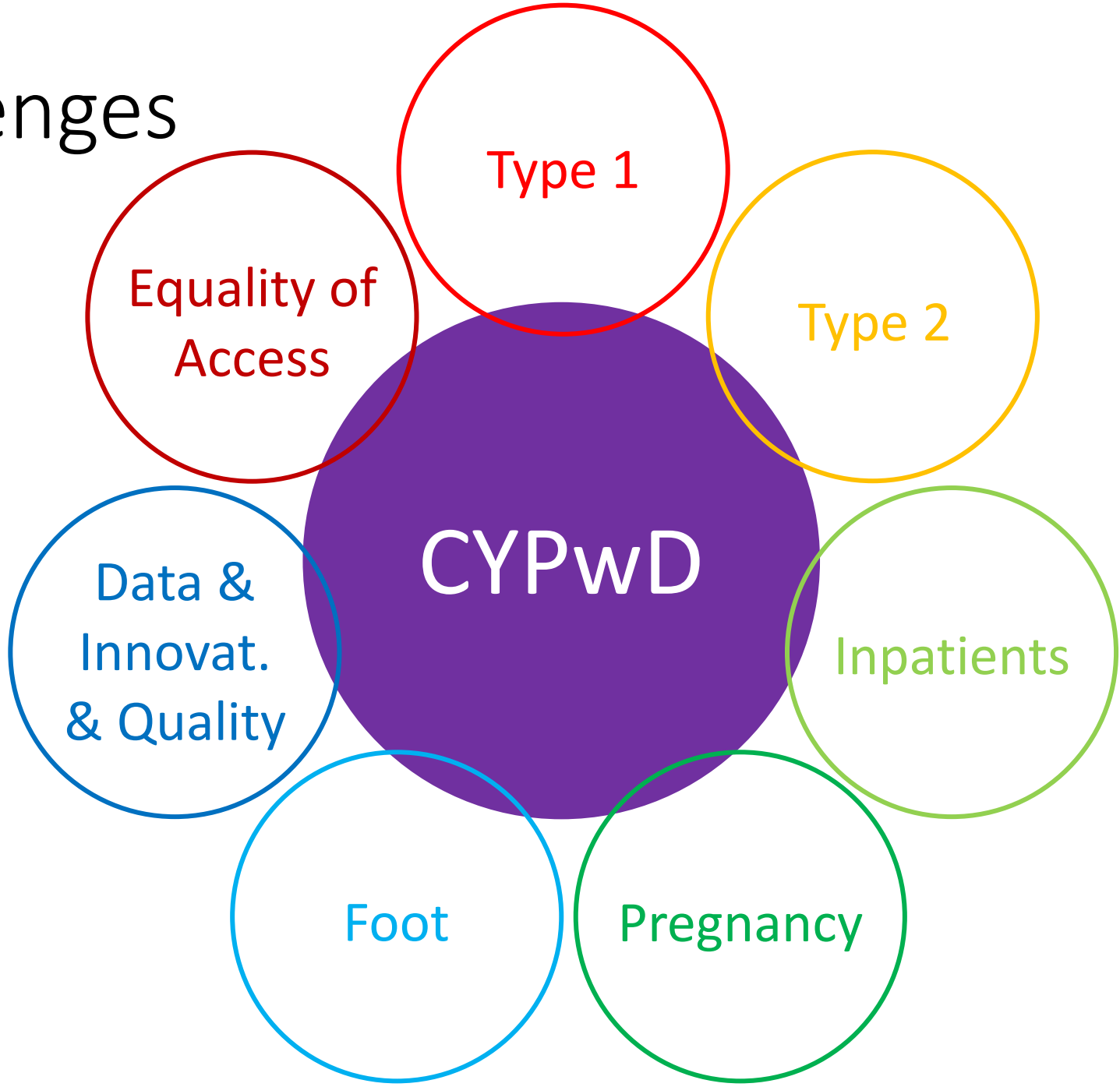


Where are we going?

- Literally
- Metaphorically

CYPwD MCN: Challenges

- Delivery of Care
  - Staffing
  - Venue
  - Standards
  - Transition
- Technology
  - Rapid changes
  - Data overload
  - Expectations
- Direction
  - Contract? Expand?
  - Stagnate? Advance?
- Moving Forward Together???



Thank you!