



NHS-Research Scotland- Children Scottish Children's Research Network

Managing paediatric clinical trials to meet the needs of the patient population within the Scottish National Health Service.

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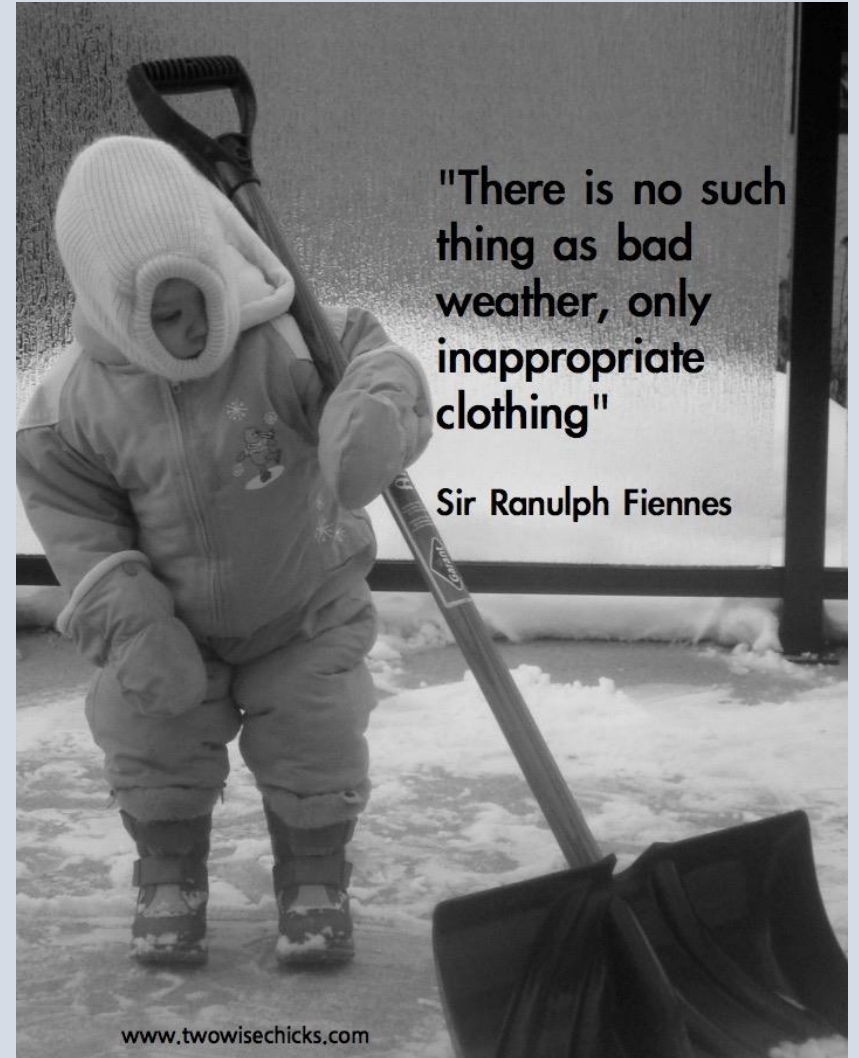
Scotland

- Population 5.2 million
- Geography 30,981 Sq miles
- Public Healthcare System
- Vaccinations free, voluntary
- Age of consent 16
 - Alcohol 18
 - Drive car 17
 - Married 16
 - Sex 16
 - Vote 16
 - Age criminal responsibility 12
 - Children's Hearing system



Finland

- Population 5.5million
- Geography 130,666 sq miles
- Public Healthcare System
- Vaccinations free, voluntary
- Age of consent
 - Married 18
 - Sex 16
 - Vote 18
 - Drive car 18
 - Age criminal responsibility 15



"There is no such thing as bad weather, only inappropriate clothing"

Sir Ranulph Fiennes



Scotland becomes first country in UK to ban smacking of ...

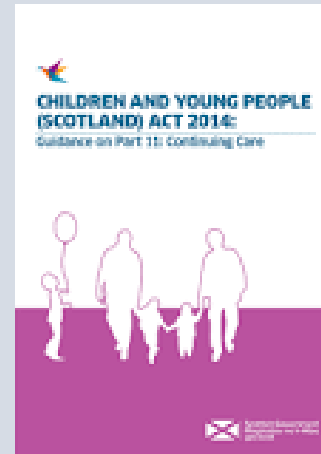
The Guardian - 3 Oct 2019

The **Scottish** government's children's minister, Maree Todd, insisted that the ... of a wholesale shift in attitudes to child rearing and **children's rights** over ... **Nicola Sturgeon's** commitment to incorporate the UNCRC into **Scots** law ...

'Equal Protection' campaigners say @ScotGov must back up ...
CommonSpace - 3 Oct 2019

[View all](#)

The **Children's & Young People (Scotland) Act 2014** is the most significant piece of **legislation** affecting **children and young people** since The **Children (Scotland) Act 1995**. It covers a range of areas, including: ... Well-being and Getting It Right For Every **Child** (GIRFEC) Youth justice, children's rights, early learning and childcare.




"All the UK nations would do well to follow the example of Scotland's 'Getting it right for every child' framework, an overarching child health strategy which unifies and coordinates policies, services and programmes for children and young people."

Source – Nuffield Trust, International comparisons of health and wellbeing in early childhood (2018)

Scottish Healthcare System

National
Health Service
Free at point of
entry

Most common chronic conditions

Respiratory
Diabetes
Gastroenterology
Rheumatology
Neurology
Obesity

Children's
Services
Age 16

17%
population
<16

CHI Number
Cradle to grave



Remit:

To **promote and facilitate** high quality clinical trials to **improve the availability, efficacy and safety** of medicines and health care for children in Scotland.

All paediatric specialties ex oncology

Core funding Scottish Government since 2006

Core staff

National	Aberdeen	Dundee	Edinburgh	Glasgow
Clinical Director J Schwarze	Champion S Turner	Champion M Kirkpatrick	Champion S Cunningham	Champion S Zuberi
National Manager P Dicks				
Pharmacist J Subedi				
	Lead Nurse M Connon	Lead Nurse S Macfarlane	Lead Nurse D Millar	Lead Nurse L Waxman
	Nurse Team	Nurse Team	Nurse Team	Nurse Team



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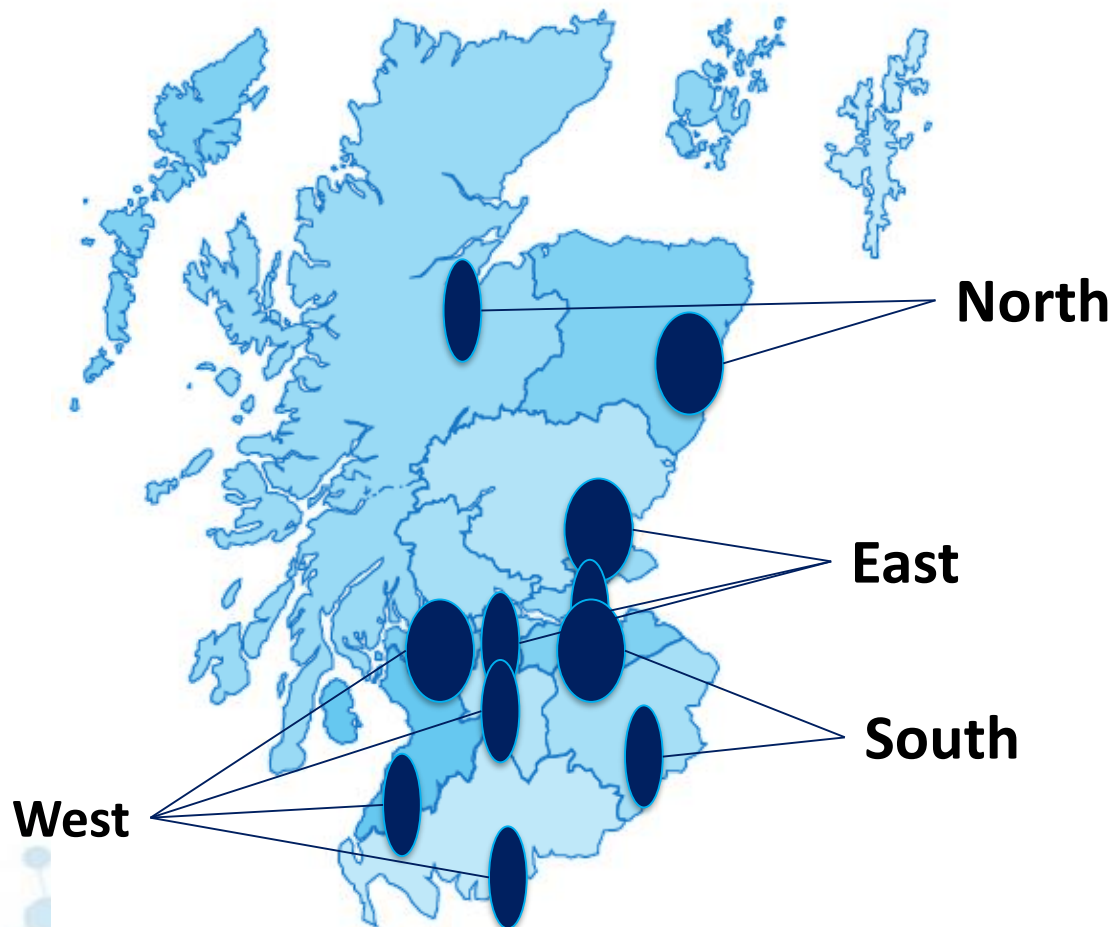
All paediatric specialties ex
oncology



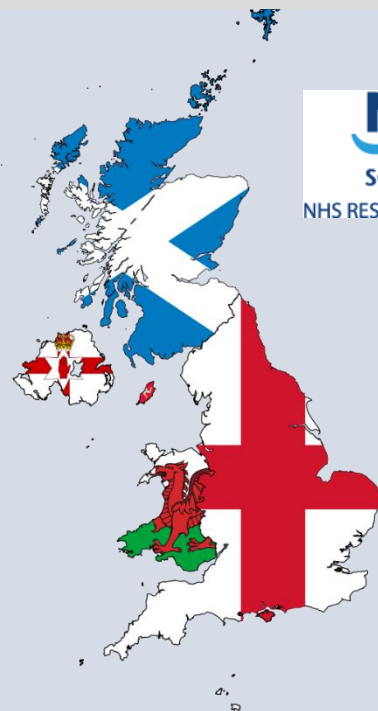
HOW

- **Feasibilities – identify right people**
- **Support consultants – research nurses and governance**
- **Promote Scotland with industry**
- **Liaise with UK and EU partners, networks**
- **Encourage naïve researchers**
- **Support protocol development, PIS**
- **Provide training in consent and assent of children to clinical trials**

- Healthcare is devolved to the Scottish Government
- NHS Scotland consists of:
 - 14 Geographic Health Boards
- 4 Research hubs
 - R&D Local Permissions
 - *Office in each Board*
 - Ethics
 - Biorepositories
 - Data Safe Havens
- National Support
 - Central Management Team
 - NRS Network
 - Permissions Coordinating Centre



Within UK



Health devolved matter

Health Boards – different legal system

Partnership collaboration- NIHR- Children's theme- GenerationR

Shared processes – feasibility, costing, approvals

Within Europe



Member – coordinating group,
working groups

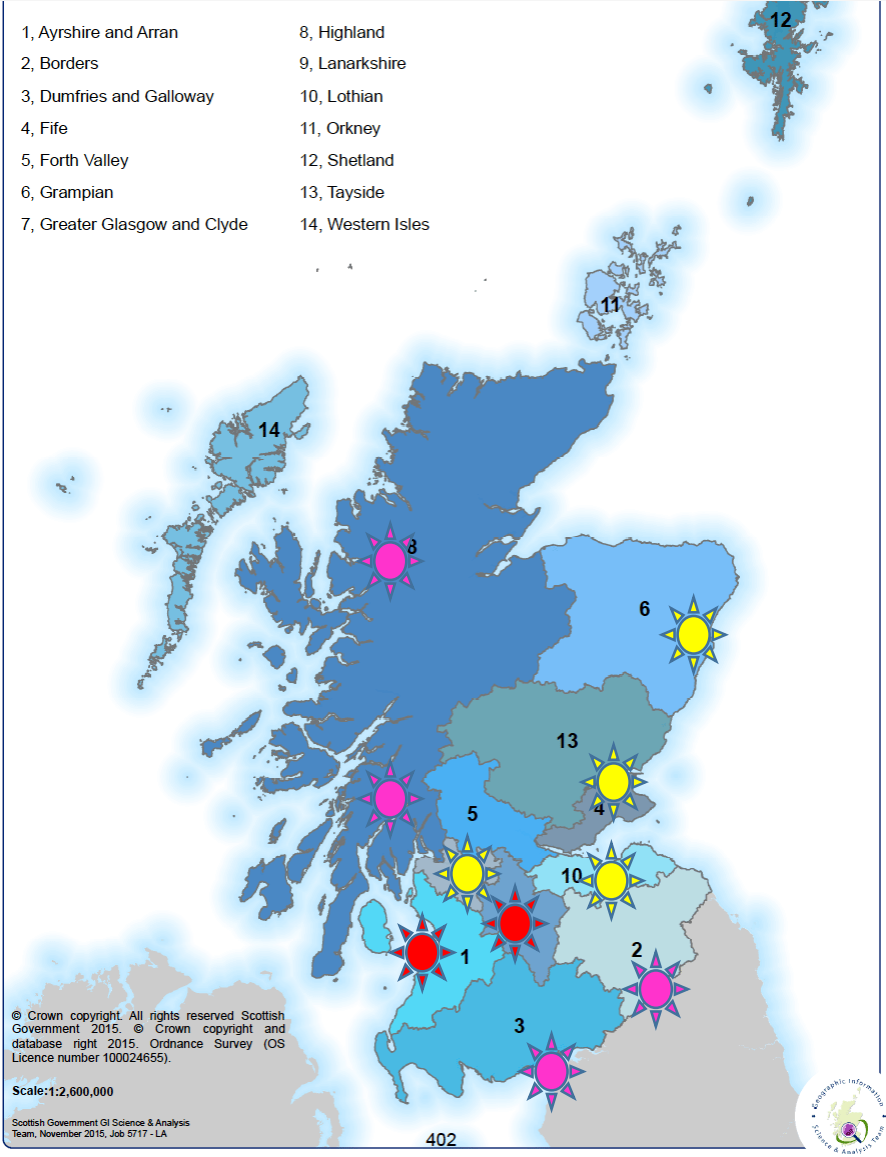


UK Hub
3rd part member PPI






Co founder Young Persons and
Patient Involvement

National Health Scotland - Delivery of Clinical Services

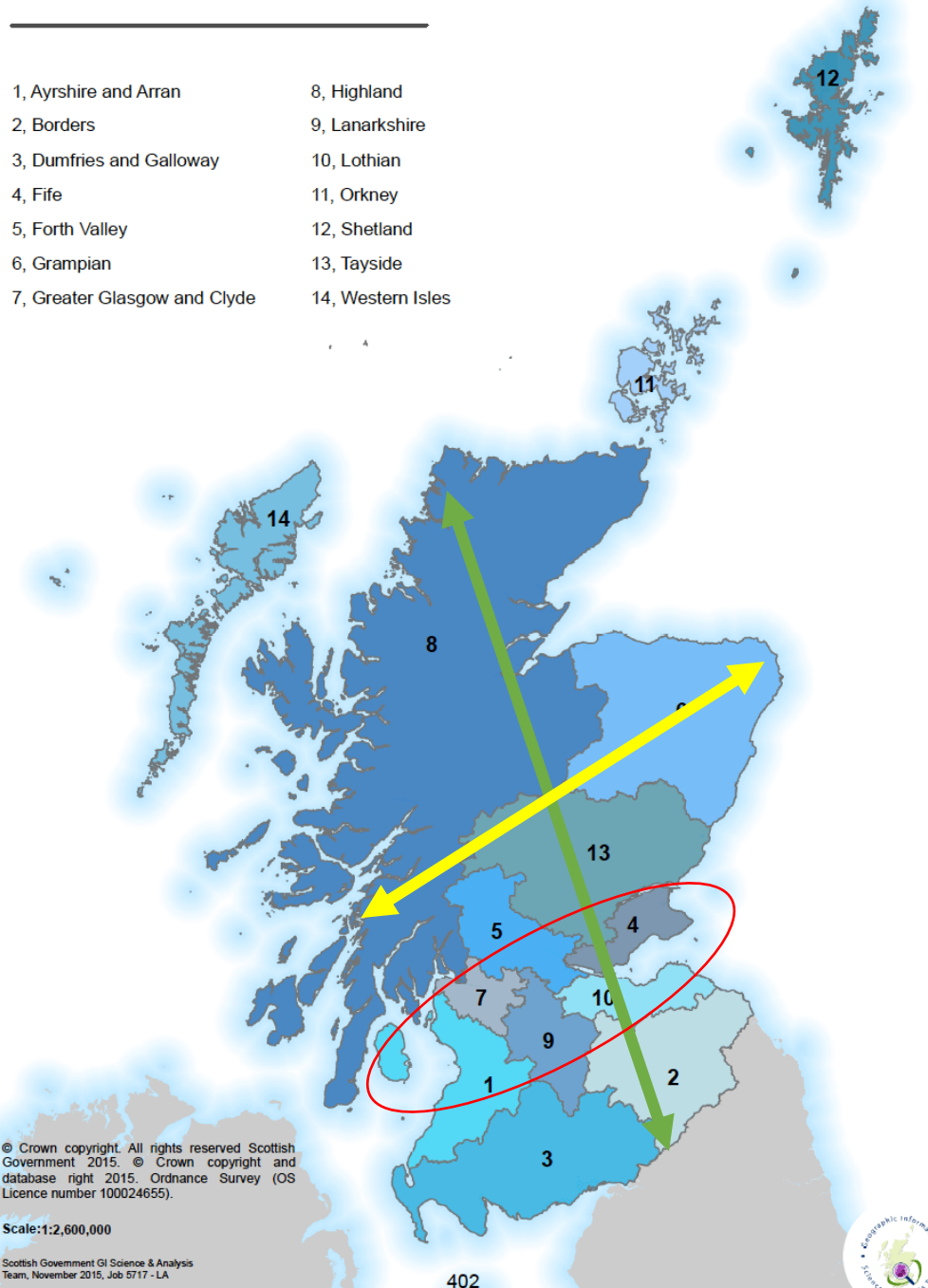


NHS Hospitals

	Clinical	Research
	Children's Hospital	Dedicated Clinical Research Facility
	District General with children's services	Paediatric Research Nurses
	District General with children's services	

NHS Health Board Areas

- 1, Ayrshire and Arran
- 2, Borders
- 3, Dumfries and Galloway
- 4, Fife
- 5, Forth Valley
- 6, Grampian
- 7, Greater Glasgow and Clyde
- 8, Highland
- 9, Lanarkshire
- 10, Lothian
- 11, Orkney
- 12, Shetland
- 13, Tayside
- 14, Western Isles



	Health Board	<16years
1	Ayrshire and Arran	61
2	Borders	19
3	Dumfries and Galloway	23
4	Western isles	4
5	Fife	64
6	Forth Valley	52
7	Grampian	100
8	Greater Glasgow and Clyde	197
9	Highland	52
10	Lanarkshire	118
11	Lothian	150
12	Orkney	4
13	Shetland	4
14	Tayside	68



	6 hours
	5 hours

Children's Hospital Facilities

**Royal Aberdeen
Children's
Hospital**



Trauma Centre Acute
Services
Secondary care centre
Paed Surgery
High dependency unit

**Clinical Research
Facility**

**Tayside Children's
Hospital**



Acute Services
Secondary care centre
Paed Surgery

Shared **Clinical
Research Facility**

**Royal Edinburgh Sick
Children**



Accident and
Emergency
Acute medical and
surgical
Specialist medical and
surgical
Intensive care unit

**Clinical Research
Facility**

Phase 1 accreditation

**Glasgow Royal Sick
Children**



Accident and
Emergency
Acute medical and
surgical
Specialist medical
and surgical
Intensive care unit

**Clinical Research
Facility**

Phase 1

Overnight facilities

**District General
Hospitals**

Acute
Services
Consultant
clinics
Secondary
care centre
Paed Surgery

CSO

Central

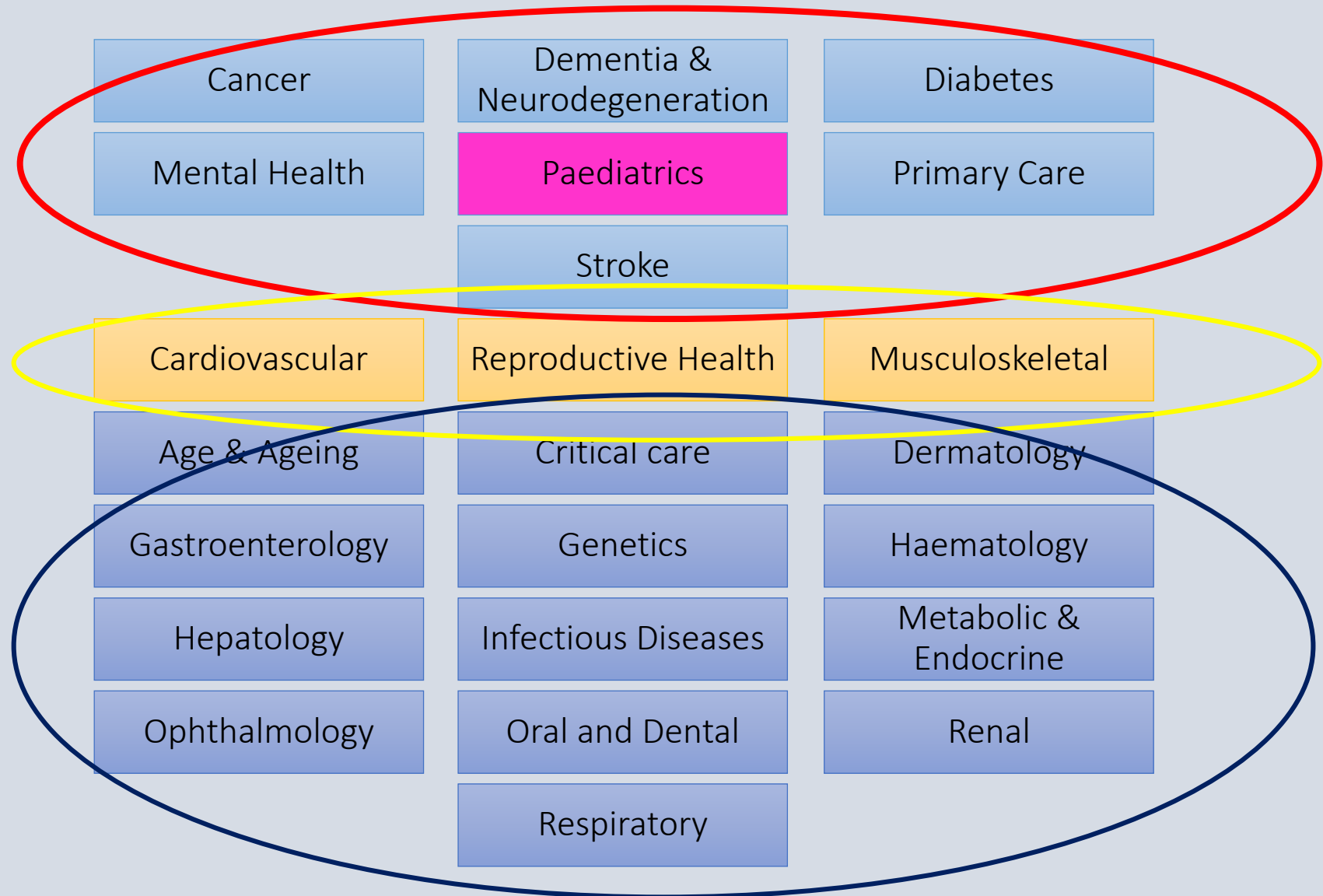
Management Team

Boards

Funding from government

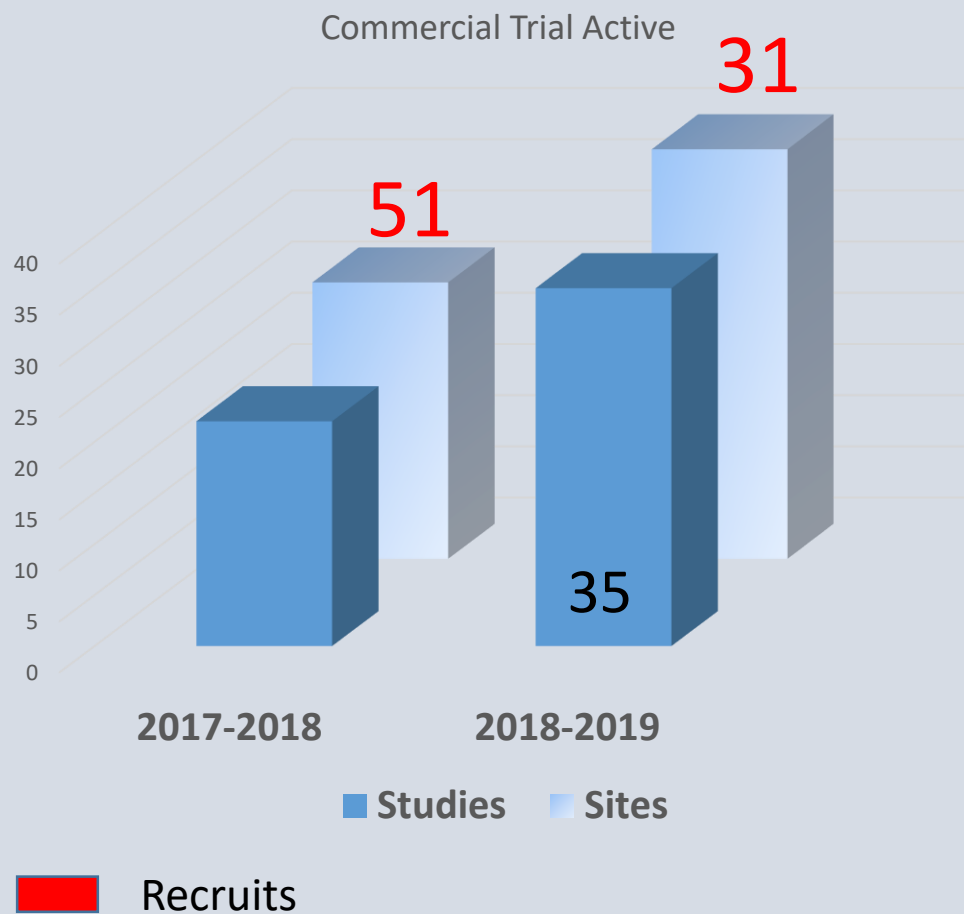
- CSO provides **funding** to Health Boards to:
 - Support and develop clinical research
 - Meet certain costs
 - Provide review and approval systems
- Terms are set out in SLAs with participating Boards
- **CMT provide a national point of contact and collection of all data**
- National Support
 - Central Management Team
 - **NRS Networks**

The NRS Networks



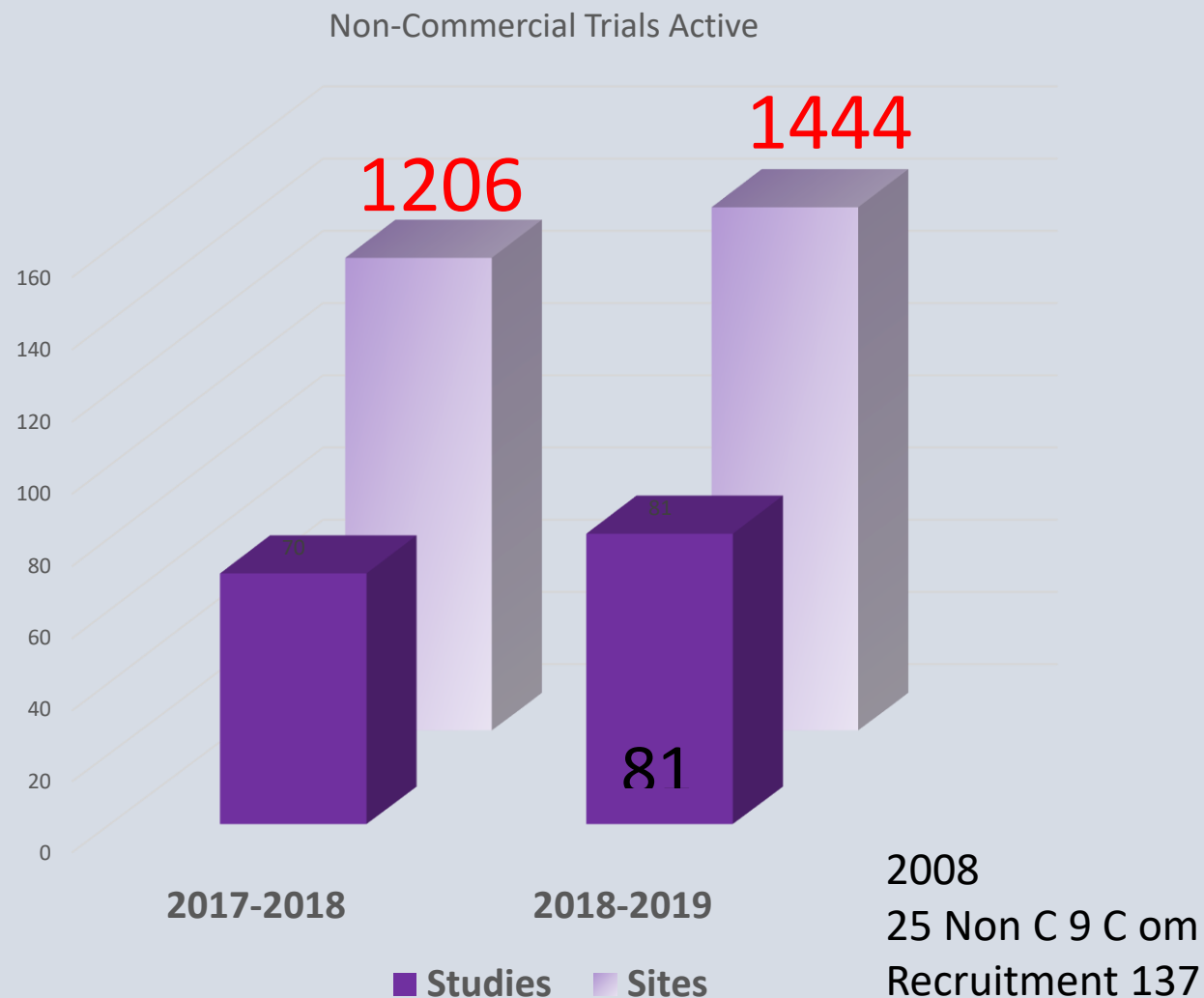
Commercial Trials

Open to recruitment
Under 18 years
(Not oncology)



Non-Commercial Trials

Open to recruitment
Under 18 years
Not oncology



Staff and Activity At Each Site

Clinical Research Facility	Total WTE	Comm Trials	Public Trials	Trials/WTE
Aberdeen	2.93 (2)	4	17	7.2
Dundee	2.1 (1.6)	3	21	11.4
Edinburgh *	7.0 (2)	5	29	5.7
Glasgow	6.5 (2)	15	32	7.2
Ayrshire	0.8 (0.5)	0	5	6.25
Lanarkshire	0.6 (0.6)	0	4	6.7



Require reactive, flexible, trained workforce.

FUNDING MODEL

SOURCE	CHALLENGE
Core Funding of Network 430k	Not enough
Local Health Board Research and Development Funding	Generic -not paed Competition other networks
Commercial	Per patient fee based on recruitment
Public - Charity	Per patient fee based on recruitment
	Staff costs up front
	Retaining Staff
Reactive, flexible, trained workforce Sustainability	



ADVANTAGES

- Increases availability of new medicines, latest developments
- Improves standards within clinical team
- Recruitment of high quality staff
- Ethical requirement of licensing

THE CHALLENGES

- Retention of staff between trials
- Fragility of small teams
- Equity of access for patients
- Remote populations
 - travel, time, work, siblings

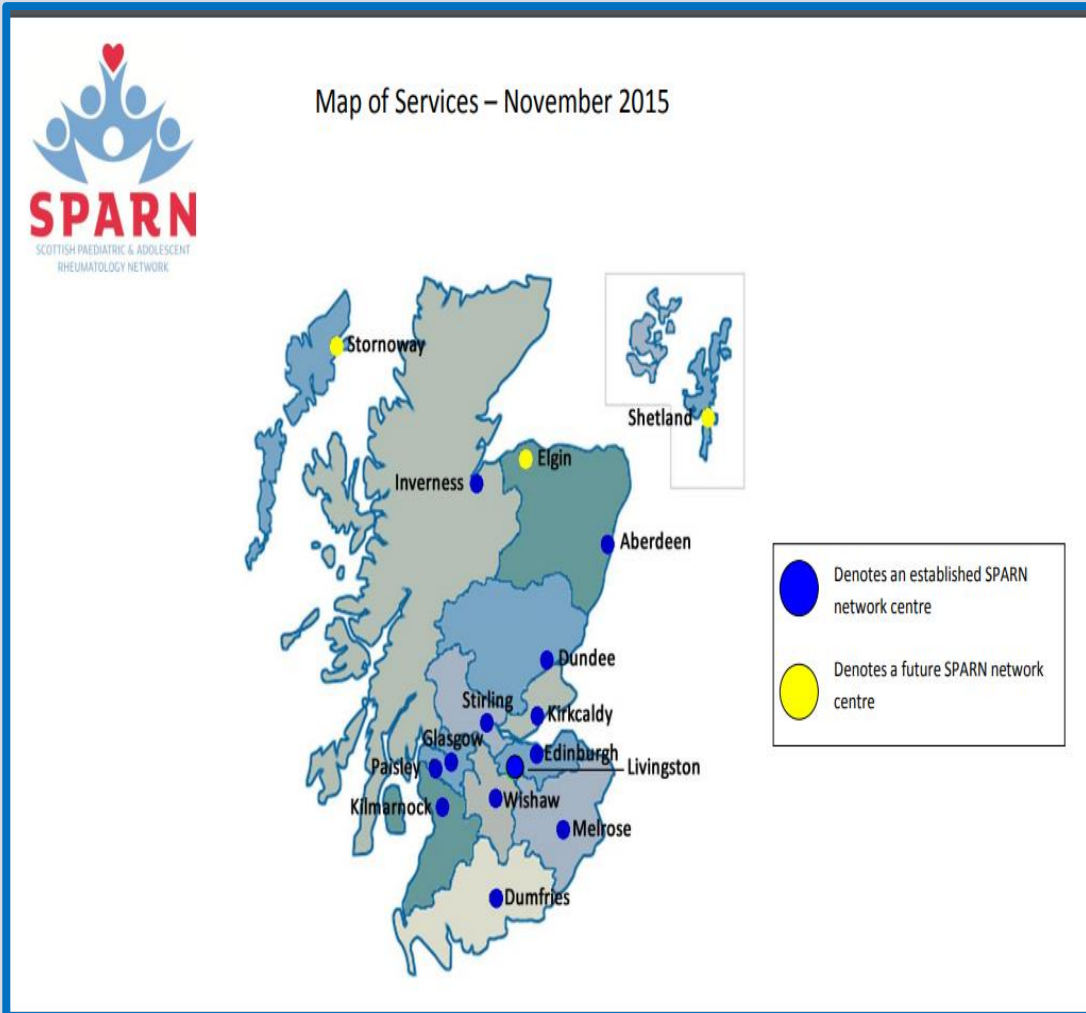


ADVANTAGES

- It's a small world
- Feasibility and capabilities
- Children managed in MCN
- Equity of access to care for patients
- National initiatives
- Close to our government departments



Managed Clinical Networks



To ensure that all children with rheumatic conditions are diagnosed promptly and managed appropriately.

The care for children with rheumatic conditions will be delivered by multidisciplinary local teams with input from paediatric rheumatologist at network clinics.

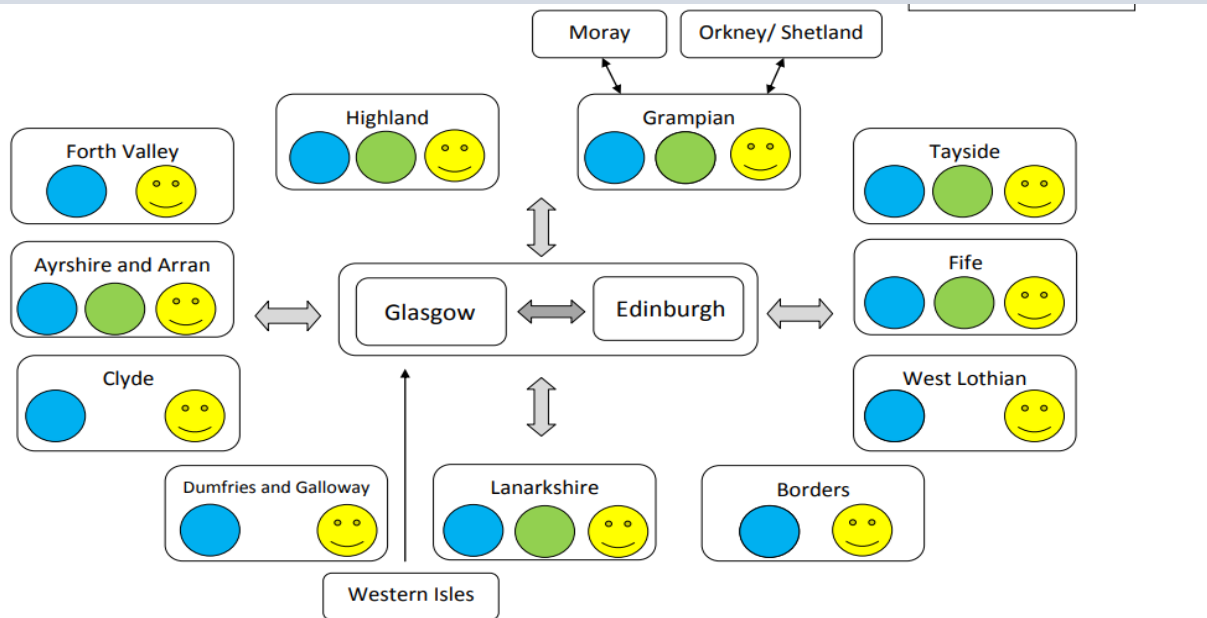
The network's aims are:




To **promote equity of access** to the best possible care for all children with rheumatic conditions in Scotland regardless of geography

To support **local delivery of care** where possible through the establishment of a network of services with locally based specialist multidisciplinary teams working in partnership with expert teams from the tertiary centres

To ensure that care delivered meets **agreed national standards of care**

To support services in improving standards of care through the establishment of continuous quality improvement



Legend	
	Denotes network clinic sessions alongside visiting consultant
	Denotes dedicated paediatric rheumatology clinics led by local teams
	Recognised as a "network clinic" service provided by recommended minimum core team*

What does it involve?

Specialist Paediatric Rheumatology Consultants



Virtual management



Multi Disciplinary Teams- Physiotherapy, OT, ophthalmology, PSN



Service Legal Agreements, contracts between Health Boards

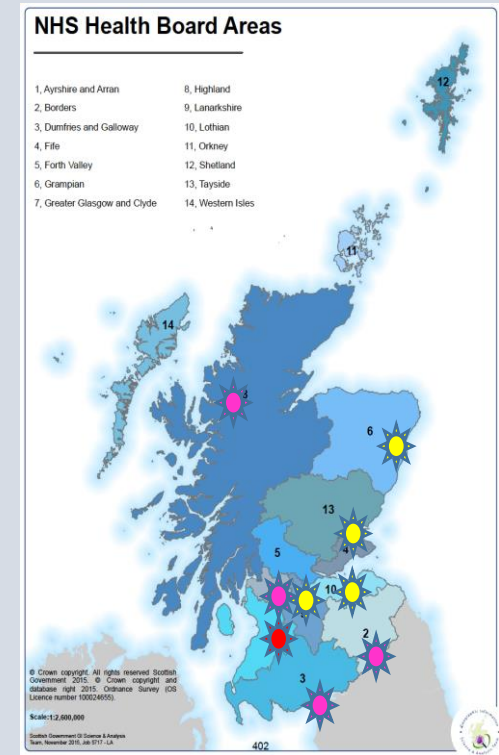
Remit:

To promote and facilitate high quality clinical trials to improve the availability, efficacy and safety of medicines and health care for children in Scotland.

How do we continue to improve?

To increase number of and recruitment and retention to paediatric trials.

How do we ensure equity of access to trials?



BE BRAVE...

Think beyond the specialist centres

Set up research trials where the patient population is.

To **really meet the needs** of the paediatric population

- Shared care arrangements
- Local sites – activities within their local expertise
- Data sharing – images, CRF
- PI – managing multiple sites
- Proportionate monitoring- remote
- Supporting sites



CHALLENGES **AND** ADVANTAGES IN BEING SMALL





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*Thank you for
listening*

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