UK National Screening Committee

NHS Screening Programmes

Sickle Cell and Thalassaemia

Sickle cell & thalassaemia screening programme update

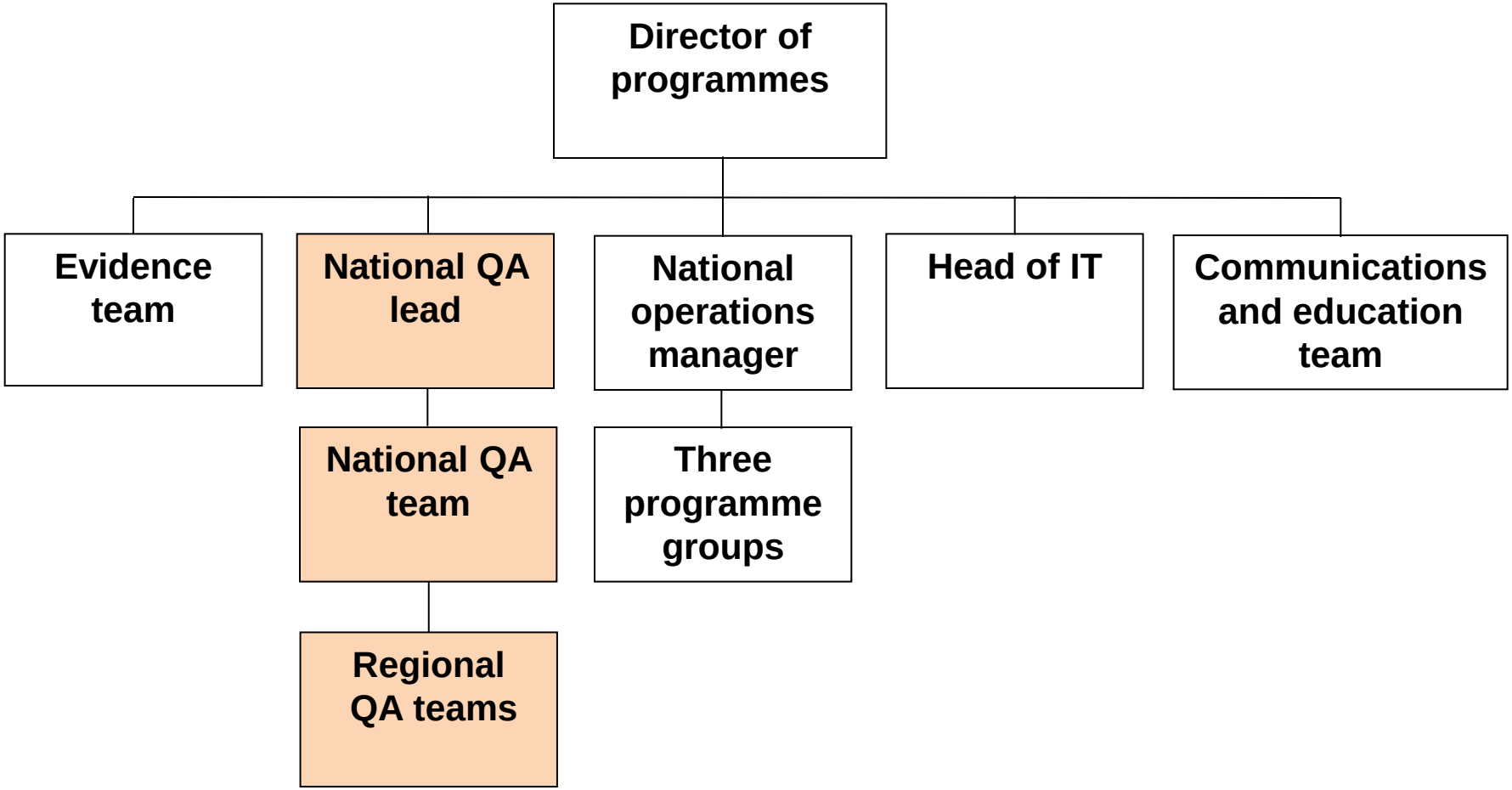
Haemoglobinopathy Forum
14th May 2014

Part of Public Health England

Aims

- Who we are and what we do
- Programme performance (data report 2012/3; England only)
- Programme work streams

UK National Screening Committee



What do we do

- Appraising the evidence and setting policy
- Implementing new policy
- Developing detailed service specifications
- Setting aims and objectives
- Developing standards and guidelines
- Developing parent education resources
- Organising publicity, information and communication
- Development and maintenance of systems for information management
- Data collection, analysis and reporting
- Quality assurance of the whole screening pathway

NHS screening programmes

Antenatal and newborn		Adult and young persons
 Infectious diseases in pregnancy	 Fetal anomoly	 Diabetic eye
 Sickle cell and thalassaemia	 Newborn hearing	 Abdominal aortic aneurysm
 Newborn blood spot	 Newborn and infant physical exam	

The sickle cell & thalassaemia team

National programmes lead

Andrew Rostron

Programme manager

Cathy Coppinger

Data manager

Matt Charlton

Project lead

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Project support

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Elizabeth Dormandy

Laboratory leads

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Clinical leads

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Programme aims

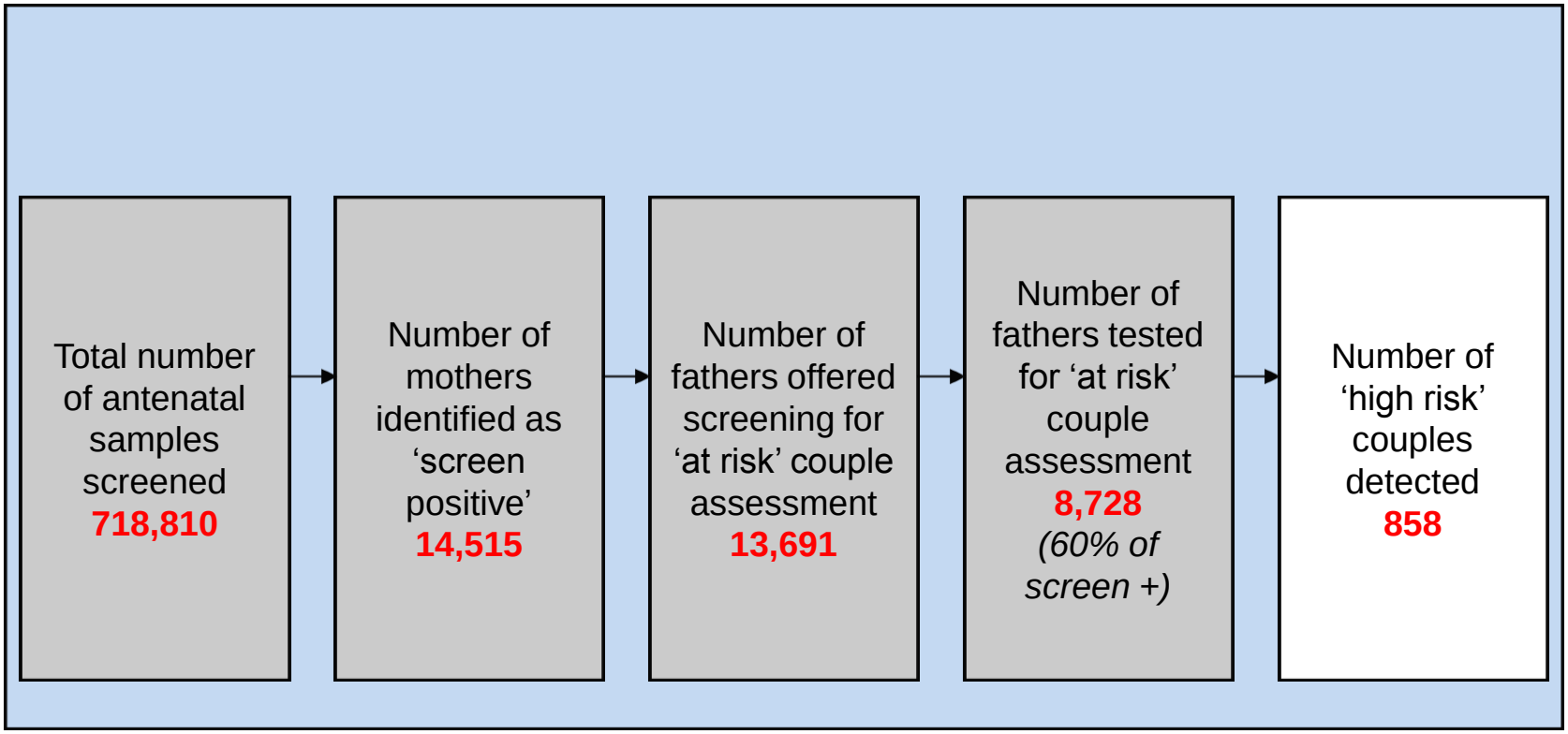
- Support people to make informed choices during pregnancy and before conception
- Improve infant health through prompt identification of affected babies
- Ensure high quality, accessible care throughout England
- Promote greater understanding and awareness of the conditions and the value of screening

Scope of screening

STARTS

ENDS

Programme performance: Antenatal

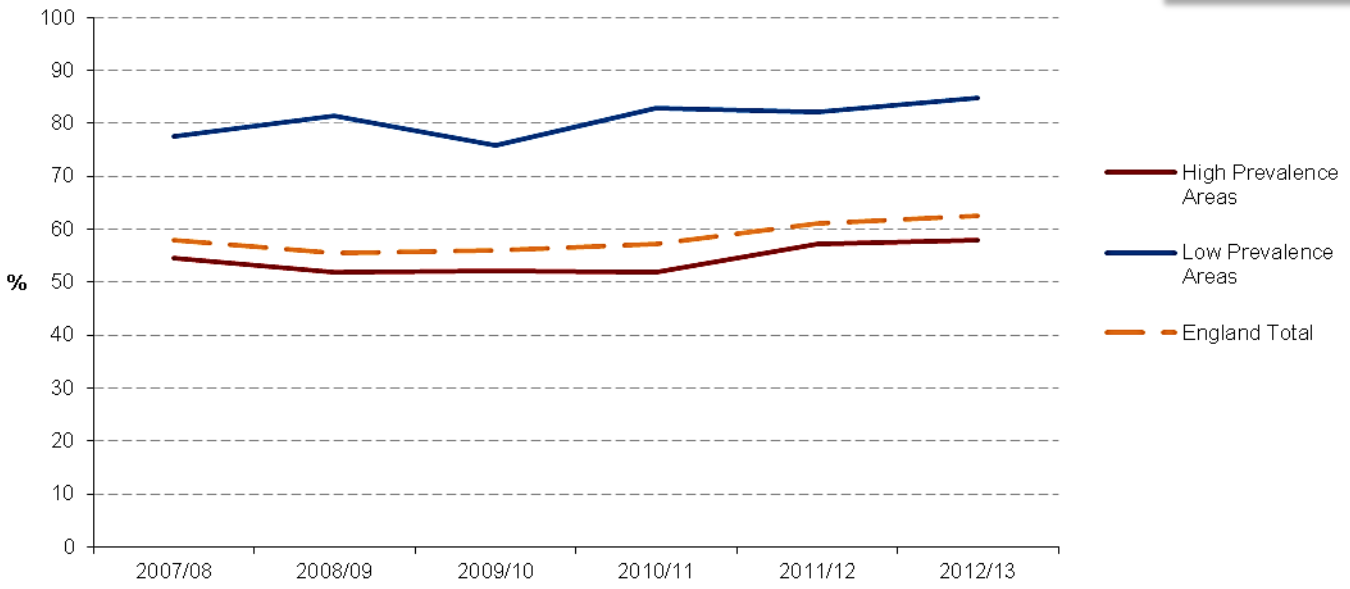


Key performance indicators

KPI Description	Acceptable threshold	Q1 2013/14	Q2 2013/14
Antenatal coverage (%)	≥ 95.0%	98.2%	98.3%
Timeliness of test (%)	≥ 50.0%	48.7%	51.0%
Completion of FOQ (%)	≥ 90.0%	95.2%	95.0%

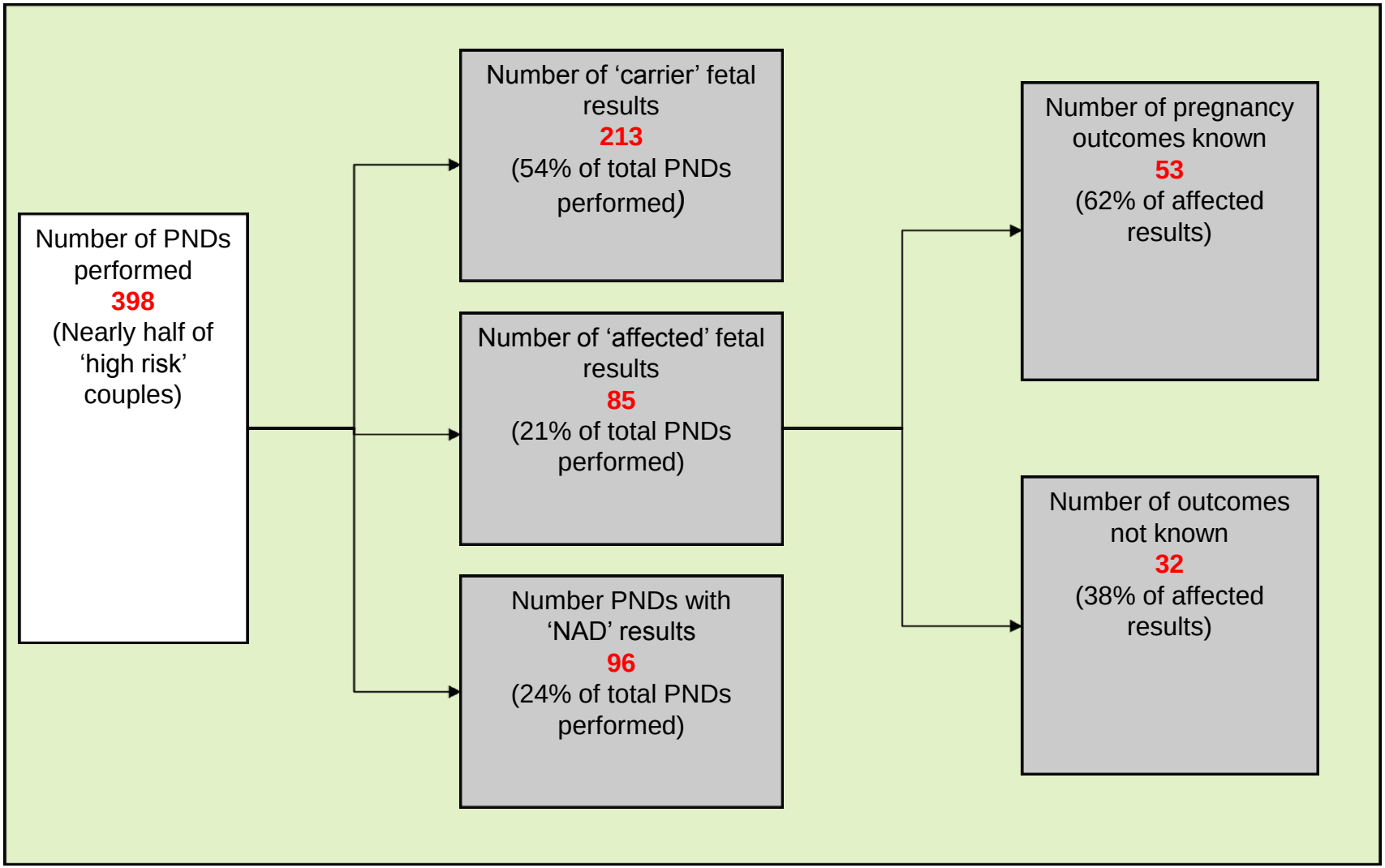
Uptake in father testing

60% of screen +ve women



Exclusions based on missing or unavailable data: 2007/08: 19; 2008/09: 10; 2009/10: 7; 2010/11: 3; 2011/12: 6; 2012/13: 6.

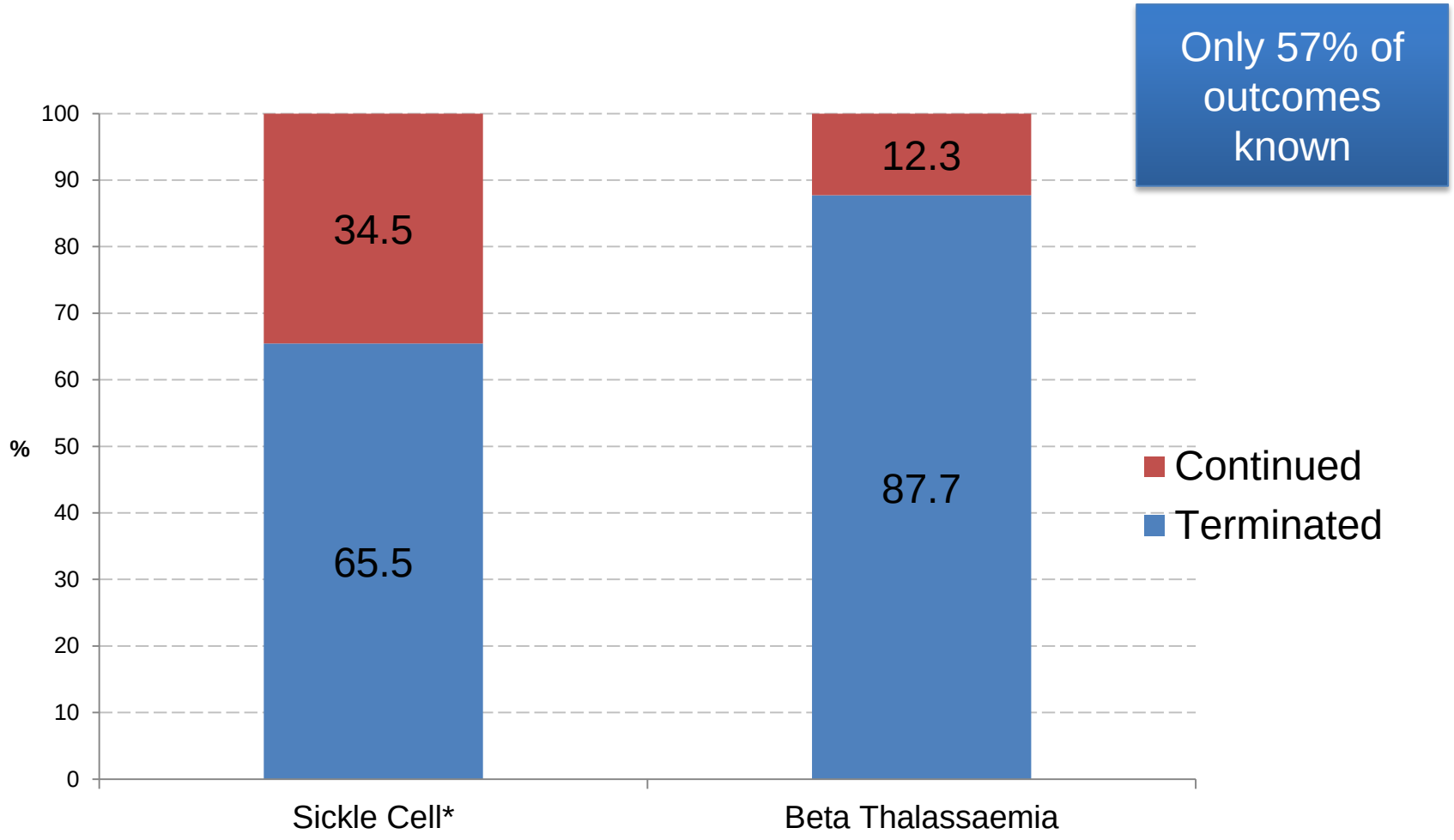
Prenatal diagnosis



Gestation at sample for PND, 2007-13

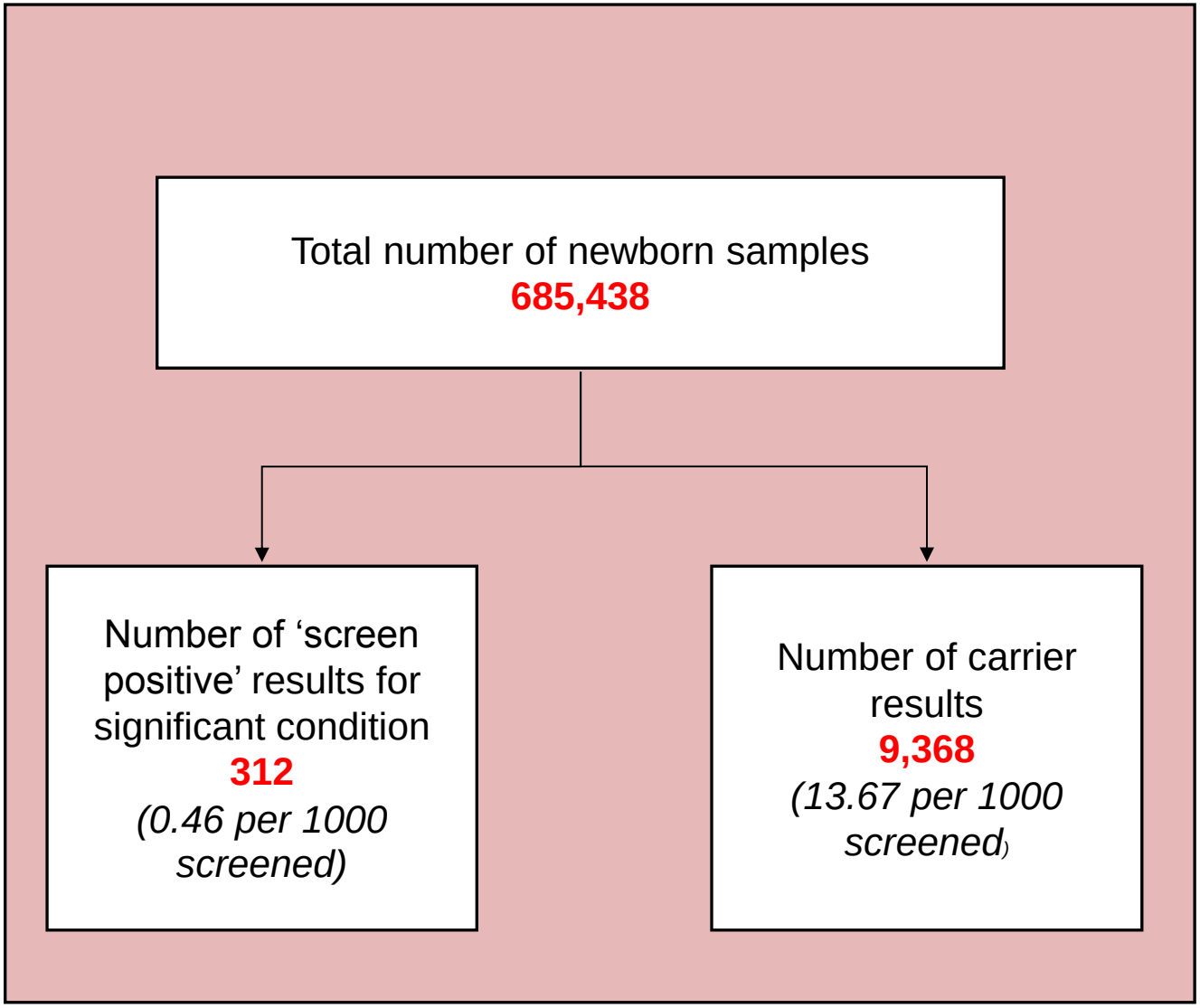
Gestation	2007/08		2008/09		2009/10		2010/11		2011/12		2012/13	
	n	%	n	%	n	%	n	%	n	%	n	%
<12+6 weeks	150	46.2	182	47.2	199	50.3	202	48.1	219	52.4	198	49.7
13+0 - 14+6 weeks	49	15.1	65	16.8	76	19.2	105	25.0	93	22.2	71	17.8
≥15+0 weeks	93	28.6	119	30.8	110	27.8	108	25.7	98	23.4	123	30.9
Unknown gestation	33	10.2	20	5.2	11	2.8	5	1.2	8	1.9	6	1.5
Total	325	100.0	386	100.0	396	100.0	420	100.0	418	100.0	398	100.0

Pregnancy outcomes: affected babies 2008/13

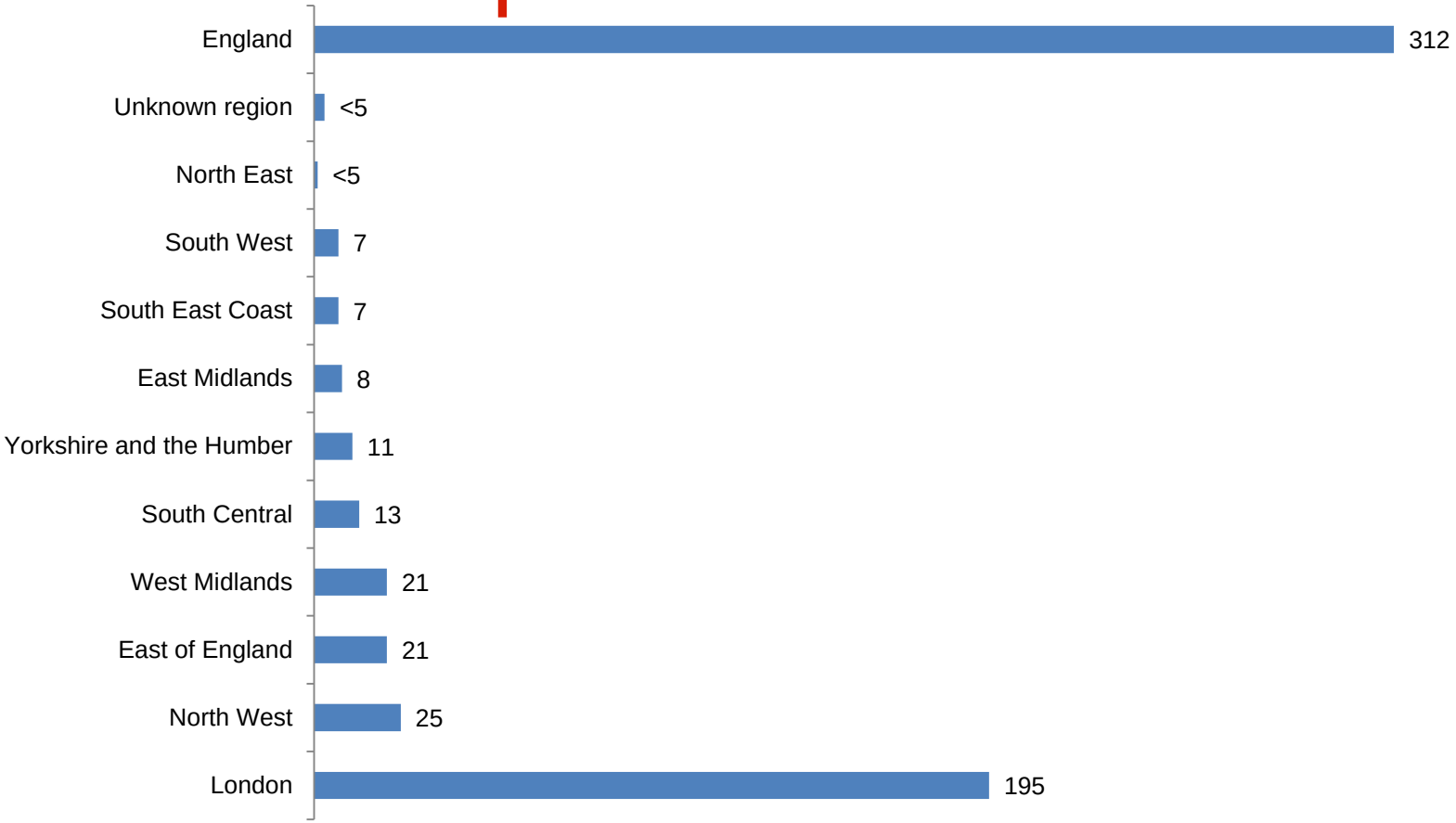


*"Sickle Cell" includes cases where the result was sickle cell and thalassaemia
Excludes alpha thalassaemia cases, miscarriage outcomes, and 174 cases where pregnancy outcome was not known.

Newborn screening

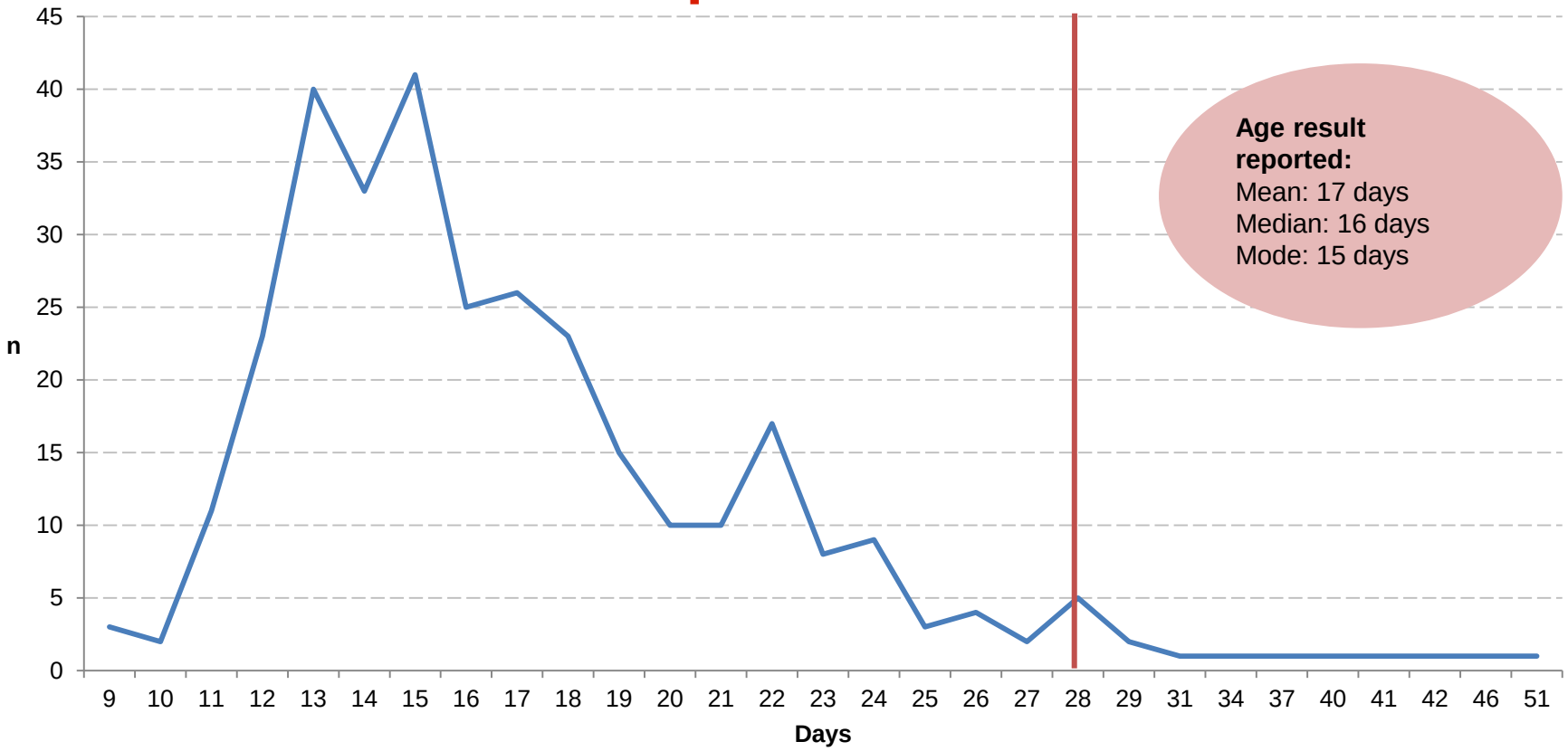


Number of babies with a screen positive result



Significant conditions comprise FS,FSC, FS Other and FE.
There were 25 F-Only cases in 2012/13 (not included above).

Age when screen positive results reported



The reference line represents the 4 week standard for Programme standard NP3. There were 326 screen positive cases reported. These data include F-only cases.

Key performance indicators

KPI Description	Acceptable Threshold	Q1 2013/14	Q2 2013/14
Newborn coverage (%)	≥ 95.0%	94.1%	93.0%
Avoidable repeats (%)	<2.0%	3.3%	3.3%
Timeliness of result (%)	≥ 95.0%	99.5%	99.5%

Programme work streams

Stakeholder engagement and outreach

- Contribute to all working groups
- Outreach resource

Laboratory projects

- Tandem Mass Spectrometry in newborn screening
- Low % A project
- Embed education into a university setting
- Consultation on storage, retention and use of retained blood spots
- Extended screening :Homocystinuria, Maple Syrup Urine Disease, Glutaric Aciduria type 1and Isovaleric Acidaemia

Improving outcome data

- Newborn outcome project
- Screening fields onto NHR Registry

Programme work streams

Information technology

- Rollout of e-foq in sites that already have Sunquest ICE in use
- Pilot/proof of concept to test integration with the laboratory information management system
- Newborn blood spot failsafe
- Antenatal Active Pathway project: antenatal failsafe

Programme work streams

Communication

- Two new leaflets for parent(s) at risk of having a baby with sickle cell disease or thalassaemia explaining choices and tests offered during pregnancy
- Letter for carrier mums and inviting dads for testing
- Move ‘public facing’ website content to NHS Choices

Cross programme work streams

- Re-write “Screening tests for you and your baby”
- Review programme standards
- Governance review including SCT steering group
- Quality assurance including peer review, links with UKAS and UKNEQAS to avoid duplication and gaps

Useful links

To contact the programme phe.screeninghelpdesk@nhs.net

Laboratory updates http://sct.screening.nhs.uk/labupdates

Laboratory e-learning http://sct.screening.nhs.uk/lab-elearning

Data templates and report
http://sct.screening.nhs.uk/datacollection#fileid12764

http://sct.screening.nhs.uk/data-report

Service specification
https://www.gov.uk/government/publications/public-health-commissioning-in-the-nhs-2014-to-2015