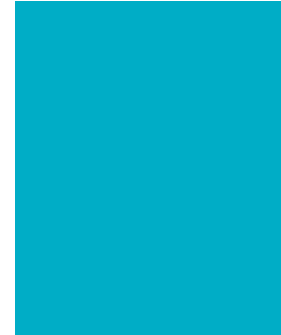


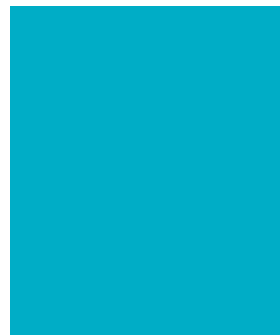
# New Congenital Heart Disease Review



## Early detection of congenital heart disease



**Clinical Advisory Panel**  
31 March 2014



## Why does this matter?

- **Early detection of congenital heart disease (CHD):**
  - improves family experience throughout pathway;
  - improves immediate postnatal management optimised by birth place at or close to a paediatric cardiac surgery centre.;
  - potentially reduces complications, morbidity and mortality associated with cardiovascular compromise subsequent to delayed diagnosis; and
  - reduces the number of emergency transfers of undiagnosed babies at birth.
- **Opportunities to increase detection at antenatal and neonatal screening**

# What do we know about antenatal detection?

- There is no single Congenital Anomaly Register.
- 2 sources of anomaly data for CHD:
  - British Isles Network of Congenital Anomaly Register (**BINOCAR**)
  - National Institute for Cardiovascular Outcomes Research (**NICOR**)
    - represent children who went on to have a procedure and only 30% of these children were diagnosed antenatally.
- Public Health England (PHE) intend to develop a national registry to give full national coverage.

## BINOCAR coverage

Proportion of births covered by regional congenital anomaly registers:  
country percentage coverage

<b>England</b>	<b>49</b>
<b>Ireland</b>	52
<b>Scotland</b>	24
<b>Wales</b>	100

## BINOCAR: Current contributors



**NorCAS:** Northern Congenital Abnormality Survey

**YHCAR:** Yorkshire & Humber CAR – **funding lost and currently not contributing – recruitment started to res establish the service**

**EMSYCAR:** East Midlands and South Yorkshire CAR

**WMCAR:** West Midlands CAR

**CARIS:** Welsh CAR

**CAROBB:** CAR for Oxfordshire, Berkshire and Buckinghamshire

**SWCAR:** South West CAR

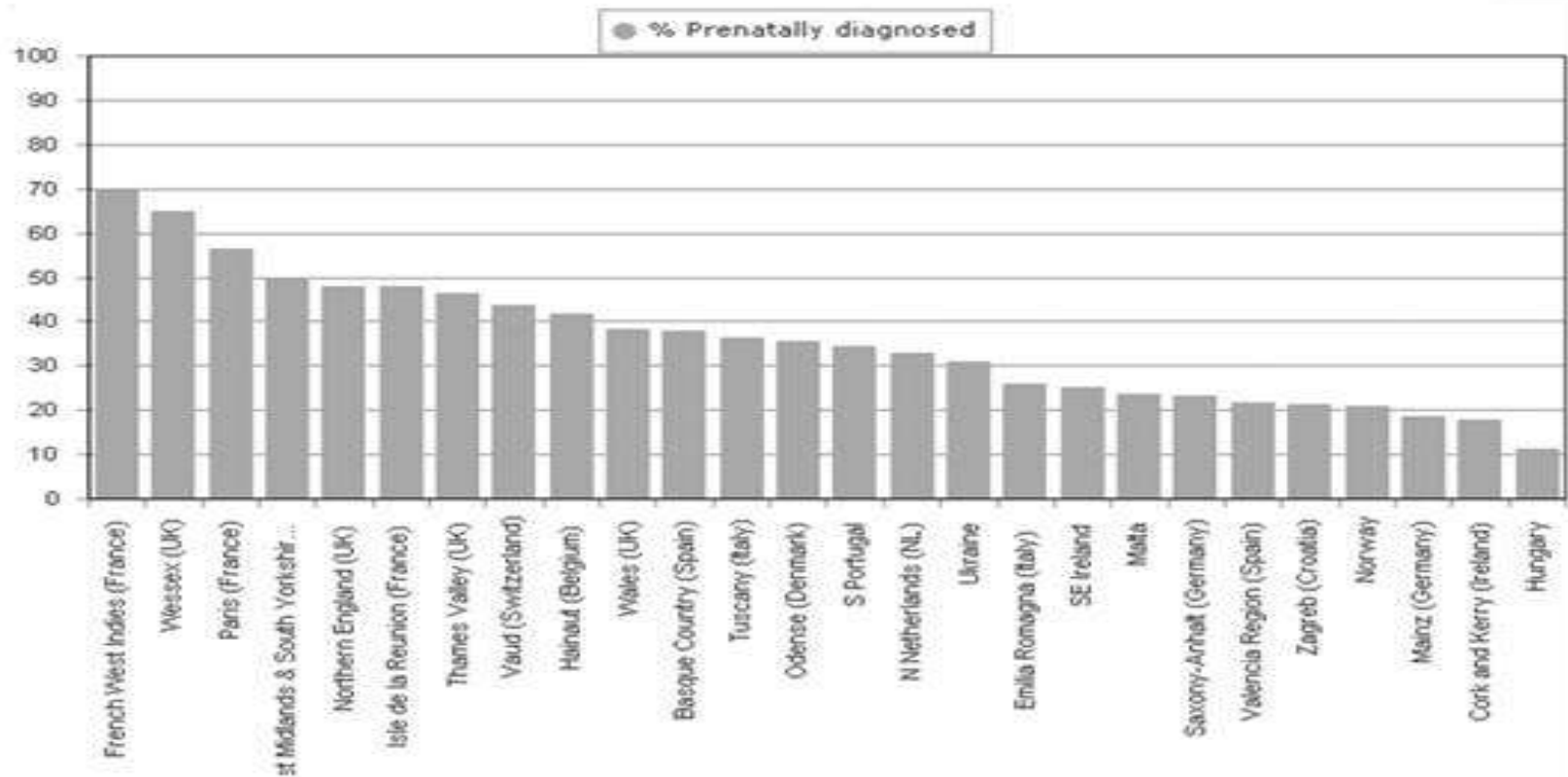
**WANDA:** Wessex Antenatally Detected Anomalies Register

## Glossary of lesions reported by BINOCAR

- Common arterial truncus
- Transposition of great vessels
- Single ventricle
- Atrioventricular septal defect
- Tetralogy of Fallot
- Tricuspid atresia and stenosis
- Pulmonary valve atresia
- Coarctation of aorta
- Total anomalous pulmonary venous return
- Aortic valve atresia / stenosis
- Hypoplastic left or right heart
- Ebstein's abnormality

## Detection results by region

Proportion of All Anomalies (Excluding chromosomal) cases prenatally diagnosed, 2008-2012



# Results

- Variation in results depend on type of defect, expertise of person screening, standards of equipment, gestation and maternal Body Mass Index (BMI).
  
- Variable uptake of national (FASP) guidelines.



## Neonatal screening

- Newborn screening detects less than half of all CHDs before discharge home.
- Proposal to add **pulse oximetry** to new-born and infant physical examination (NIPE) to pick up more cases of CHD who are likely to present clinically between 24 and 48 hours after birth.
- UK National Screening Committee review of neonatal testing completed in March 2014; recommendation not known.
- Currently 1 in 5 hospitals have implemented the test.

## Pulse oximetry

- Evidence suggests pulse oximetry clinically useful and increases the number of CHD defects detected but optimal approach not clearly defined.
- Some concerns about “false positives” creating additional burden:
  - additional work (with resource implications) to confirm diagnosis; and
  - additional counselling / reassuring parents.

**BUT – assess the value of “preventative spend”**

## Neonatal Testing

- More information needed on management pathways for newborns with screen positive results and on the outcomes for newborns with non-cardiac conditions.
- Potential for pilots to explore the issues including:
  - the information requirements of parents and health professionals;
  - training needs for midwives and others involved in using pulse oximetry;
  - data and systems requirements for audit, quality assurance and monitoring of longer term outcomes; and
  - resource implications arising from pulse oximetry screening.

## Pulse oximetry: Case study

### **Birmingham Women's Hospital**

Implemented pulse oximetry 4 years ago:

- 8,000 deliveries a year
- 60 newborns picked up as “at risk”
- 4 out of 5 of those who test positive have a significant problem that requires medical intervention.
- 1 out of 5 perfectly healthy (i.e. 12 out of 60 p.a.)
- So only 12 out of 8,000 babies screened each year are healthy “false positives” - these are identified quickly and no further treatment required.

## Initial development of plan

- NHS England to facilitate multi-agency working to support improved antenatal detection and reporting.
  - Established co-ordinating group .
  - Provide project support.
- Stakeholder mapping.
- Scope: Map current service starting at 11 week scan and identify gaps and opportunities for improvement.

### Stakeholders

- **PHE:** screening committee and extending National Registry
- **Health Education England (HEE):** enhanced education for sonographers
- **Clinical Commissioning Groups (CCGs):** commissioning of the maternity pathway including early detection and accountability for quality, safety and clinical governance.
- **FASP/NSC:** new guidelines on screening and recommendations to connect early detection with congenital cardiac specialist services.
- **Clinical Reference Groups (Congenital Cardiac, Fetal and Maternal Medicine)**