Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland

CARDRISS

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https://www.isdscotland.org/Health-Topics/Maternity-and-Births/CARDRISS/

Background

In 2018, NHS National Services Scotland, Information Services Division (ISD) launched a 3 year project to establish the Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland (CARDRISS). This has been a long standing gap in Scotland's health data infrastructure.

The register will capture information on babies affected by a major structural or chromosomal anomaly, or an inherited endocrine, metabolic, or haematological condition covered by newborn screening. Affected live born babies diagnosed within the first year of life, fetal deaths at ≥20 weeks of pregnancy, and pregnancies terminated at any gestation will be registered.

Methodology

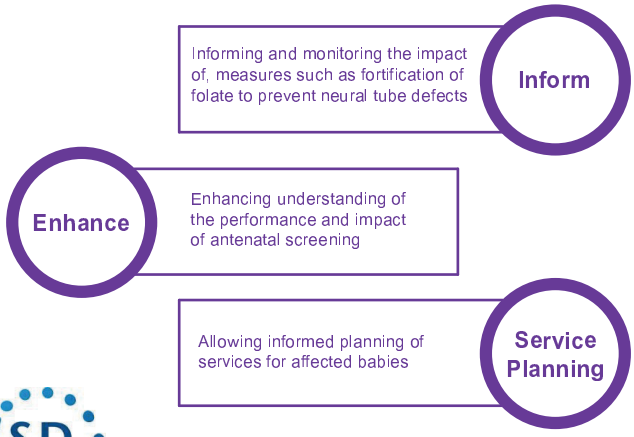
Key Project Elements:

- Assessing the extent to which existing national and local data sources can identify babies affected by anomalies
- Determining the data items to be collected
- Building a bespoke IT registration system
- Recruiting and training register staff

Project Principles

Aims

Establishing CARDRISS will enhance Scotland's health data infrastructure. In turn, this will directly support the provision of person-centred, safe, and effective care, by:



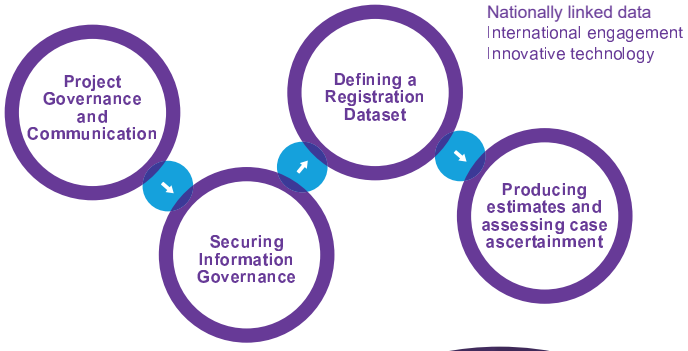
Outcomes and Results

CARDRISS will allow:

- Existing national and local data, identifying babies possibly affected by anomalies will feed into an IT system to generate provisional registration records. Additionally, clinicians will be able to notify cases directly.
- Registration staff in NHS Boards across Scotland will access clinical records to confirm the case, code it, and complete missing information.
- Finalised records will be held by ISD and used for analysis and reporting at national and local level.

Timeline to better data

At the start of a three year project CARDRISS will focus on:



Nationally linked data
International engagement
Innovative technology

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