

# Advice for Coding Downs Syndrome (Trisomy 21) screening & diagnosis in Scotland

This document contains guidance for GPs on the coding of people with a diagnosis of Down's Syndrome (Trisomy 21) and coding of screening/diagnostic tests which indicate that a woman's unborn child has Trisomy 21.

We recommend practices consider an audit to check that the correct codes are used in the correct record:

- the **screening** code should be recorded in the **mother's** record.
- the **diagnosis** code should be recorded in the **infant's** record.

Below are lists of relevant Scottish Read V2 codes.

There are reported instances where the maternal record incorrectly contains a code for Trisomy 21 when a woman's unborn child is diagnosed with Trisomy 21, rather than a diagnostic or screening test code. Similarly, infant record may not have any diagnostic code, but this is usually updated and rectified within a few weeks of birth.

This was highlighted when this dataset was used to recall COVID-19 Clinical Extremely Vulnerable Patients and could adversely affect the recall of people, **for example** with learning disabilities.

**We recommend practices consider an audit to make sure the correct codes have been used.**

Below are lists of relevant Scottish Read V2 codes.

## Diagnostic Codes

The following codes should be used where Trisomy 21 (also known as Down's Syndrome) is the **diagnosis**:

PJ0..	Down's syndrome - trisomy 21
PJ00.	Trisomy 21, meiotic nondisjunction
PJ01.	Trisomy 21, mosaicism
PJ02.	Trisomy 21, translocation
PJ0z.	Down's syndrome NOS

## Screening Codes

The following **diagnostic/ screening** codes should be recorded in the maternal record (and a diagnosis of Trisomy 21 should be retracted/redacted)

44qH.	Downs screening test
4H73.	Amniotic fetal cell: mongol
62U..	Downs screen - blood test
62U8.	Downs screening - blood sent
62U9.	Downs screen blood test normal
62UA.	Downs screen blood test abnormal
62Uz.	Downs screening blood test NOS
8CEM.	Down's syndrome antenatal screening information leaflet given

Note the code below may be present in other family member's records:

13L2.	11	Downs child in family
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(this code is a Synonym for the term 'Relative-Mental Handicap')