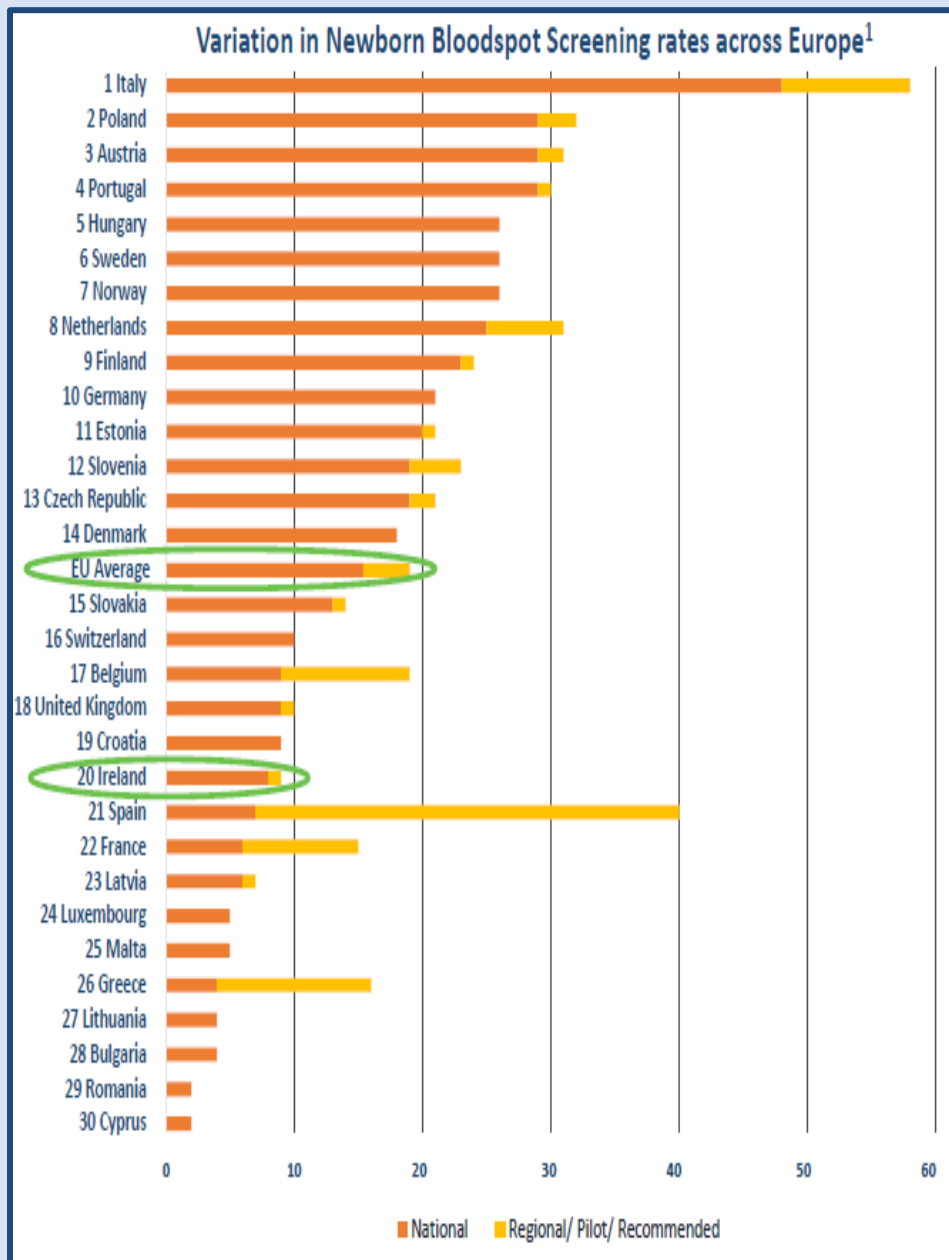


Newborn Bloodspot Screening - the 'heel prick test' - in Ireland



- The 'heel prick test' has potential to screen for 50 or more rare conditions. Ireland screens only for 8, with 1 more rare condition due to be added (22 months after recommended for addition).
- Launched in 1966, Ireland's NBS programme was one of the first globally. Ireland has fallen far behind peers across Europe and tests for only half the EU average number (16) of rare conditions.



RESEARCH²

- 51% Irish adults (72% parents) familiar with the 'heel prick test'.
- 64% parents know that the test screens for rare conditions.
- 41% parents received sufficient information from care providers at time of their newborn being screened.
- 65% parents favour screening for as many conditions as possible.
- 86% parents want to know if their newborn has a rare condition, even if they are not yet treatable & 85% parents want to know if their newborn has a condition that may not be symptomatic for many years.
- 83% of parents think that families with newborns with an increased risk of a rare condition should be able to ask for specific screening.
- Trust in healthcare system's assessment around what should be included in NBS programme is high (70%) amongst parents, but drops considerably amongst those living with rare conditions (26%).

1. from A Landscape Assessment of Newborn Screening in Europe - Published: April 4, 2022 | Tim Wilsdon, Rowan Saada and Milan Ferguson, Charles River Associates

2. Complete research report available on-line at <https://rdi.ie/nbs/>