

FOI NEWBORN SEQUENCING NUMBERS

DP-7036

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Request

I have seen 2022 news reports indicating the UK Newborn Genomes Programme will sequence the genomes of 100,000 and/or 200,000 babies, respectively. The correct number is 100,000, right? Was it initially 200,000 and then changed at some point to 100,000? (If so, when was that change made?)

Our response

As announced in the Spending Review statement of September 2020 and set out in more detail – including the specific funding commitment – by the Department of Health and Social Care in December 2021, the programme has been funded to sequence 100,000 babies' genomes in this government spending period.

The number of babies genomes will need to be sequenced through the study is determined by sample size calculations looking at the number of participants required to accurately estimate the clinical utility of newborn genome sequencing. At the time of the funding announcements, based on our early design scope, the calculations indicated a sample size of 200,000 may be needed, meaning that recruitment may have needed to extend into future government spending periods.

As we have refined our design, we have carried out updated calculations and believe that that the number of babies required is closer to 100,000. We will update our calculations ahead of launch once the list of conditions looked for is finalised and during the study as we get more real world data on the frequency of these conditions. This may further adjust this figure.