

A RETROSPECTIVE AUDIT IN DECLINE RATES IN THE SOUTH EAST THAMES SCREENING LABORATORY

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Introduction

Before a child is screened the parents are allowed to make an informed decision about whether or not to consent to testing. In some cases, the parents choose to decline screening. Statistically speaking, a positive case may be missed in a child that is not screened. For example, this year a baby that was originally declined for screening, was confirmed positive for cystic fibrosis (CF) after being referred due to clinical suspicion for CF. Although the likelihood of this happening is low, the importance of screening should still be emphasised to parents since these cases can happen.

The aim of this audit was to determine the decline rate over a selected period and to observe any trends in the decline samples that we receive.

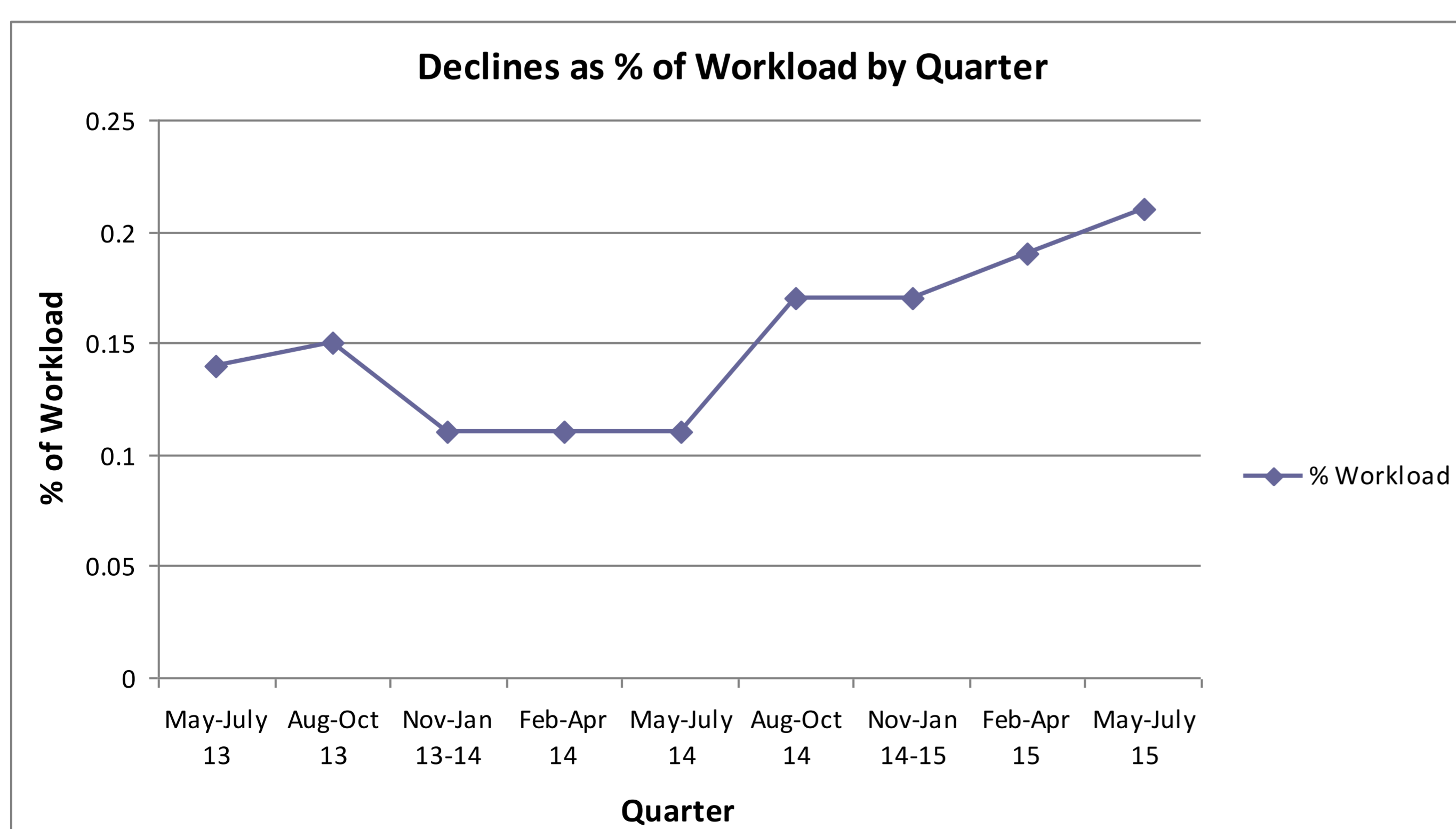
Methods

Data was collected from OMNI (St. Thomas' Newborn Screening LIMS) from 1st May 2013 to 31st July 2015. A total of 209 declines were received during this period, which represents 0.15 % of the overall workload. Data was categorised into specified time periods and by location of PCT/midwifery unit, to investigate any trends in the data.

Results

Declines by Quarter

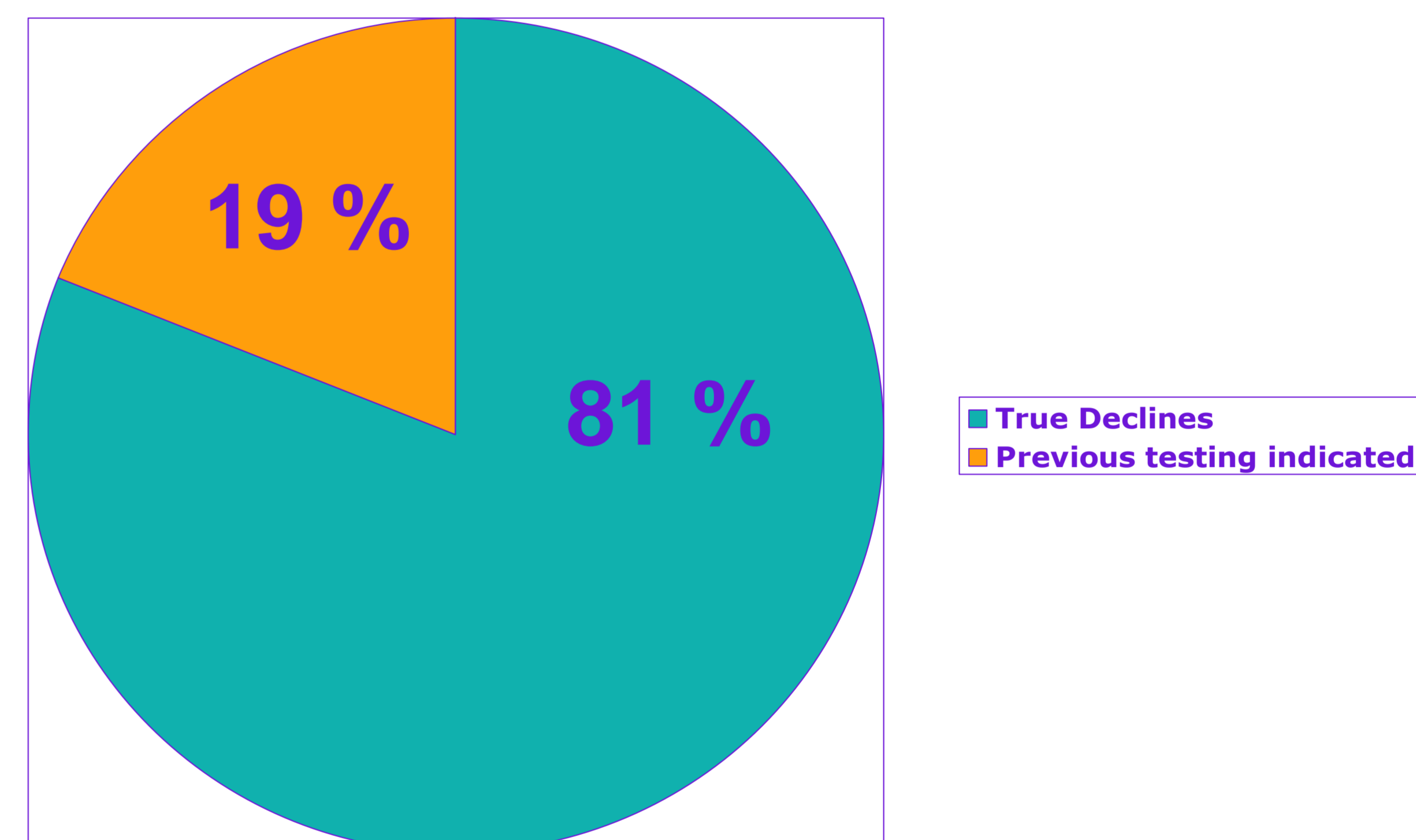
Initially the results were examined by month, and the number of declines for each month was calculated as a percentage of workload. Declines as a percentage of workload never exceeded 0.3 %, representing a very small fraction of the workload received. There were a number of spikes in the data but no clear month in which the decline rate was noticeably different. As a general trend it appears that the number of declines has increased since May 2013. However, the significance of this will only become obvious with continued review of the data.



The last quarter was looked at in detail to determine where the majority of these declines are coming from. Out of the 34 declines in May-July 2015 the majority came from the London areas: 11 came from Greenwich, 5 from Lambeth and 7 from Southwark.

Reasons for Declines

The individual bloodspot cards were then looked at to see if any reason was given for the decline. Out of the 209 declines, 197 had card images that could be analysed. For one decline, screening was offered again at a later date and results were obtained in this case. 38 declines gave the reason 'child born abroad' or 'testing previously done' as a reason for decline. The majority of the 158 remaining cards did not give a reason for declining screening. These cards can be expressed as the 'true declines' and represent 81% of the overall declines. When looking at the last quarter in isolation, 11 out of the 34 declines (32 %) were babies that were born outside of the UK, or reported to have had testing whilst outside of the UK. This is a common finding for London areas, since families will often move in and out of the London area from countries abroad.



Conclusions

The decline rate for SE Thames Newborn Screening laboratory is very low. However, the number of declines in the last six months has risen from previous quarters. 38 (19 %) of the declines were due to babies being born outside of the UK who have previously had screening elsewhere. This is therefore unlikely to be something the laboratory can influence and represents the large 'moving in' population that we see in London today. The number of true declines is therefore lower (158), representing 81 % of the total declines, or 0.1% of the total workload.

Future Work

Initially, data will be collected from the other London Newborn Screening Laboratories, to produce pan-London decline rate data. The idea for future analysis is then to compare St. Thomas' data to decline data from all UKNSLN labs. We can therefore identify whether other regions see a similar trend with large numbers of declines coming from babies born abroad, or whether this is in fact a regional occurrence.