

Cystic Fibrosis Research News

Title:

INTERNATIONAL APPROACHES FOR DELIVERY OF POSITIVE NEWBORN BLOODSPOT SCREENING RESULTS FOR CF

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What was your research question?

What are health professionals' experiences of delivering positive Newborn Bloodspot Screening (NBS) results for cystic fibrosis (CF) to families?

Why is this important?

The clinical outcomes for babies who have a positive result from NBS varies enormously and consequently the message to parents needs to be accurately presented for a range of outcomes. Previous research has shown differences in how positive NBS results are communicated to families. As most infants will not have symptoms when parents receive the positive NBS result, it is vital that they are told the result carefully to avoid negative effects on future treatment adherence and relationships with health professionals. Adherence and trust are important to ensure prompt diagnostic testing to confirm the result and swift start of treatment to maximize outcomes for the child.

What did you do?

We used semi-structured interviews and online questionnaires with a number of health professionals from different countries who are involved in communicating positive NBS results to parents. Members of the European CF Society (ECFS) Neonatal Screening Working Group (NSWG) were contacted via email before the ECFS Conference in June 2017 and invited to be interviewed at the conference. Members of the NSWG who were not at the conference, contacted the research team wishing to be involved in the study. Therefore, the interview questions were developed into an on-line questionnaire and sent out using Qualtrics Survey Software.



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What did you find?

There were big difference in how health professionals informed families of positive NBS results. This influenced the quality of the information and how much information was provided, potentially increasing anxiety and affecting timely diagnostic testing. The people answering the questions identified good practices including systems to improve the timeliness of screening and processing of results, as well as areas for improvement. They also stated that knowledge of CF and familiarity with the family were both important when deciding who should inform the family of positive NBS results.

What does this mean and reasons for caution?

It is a challenge to process and communicate positive NBS results for CF well, it requires training and experience and is influenced by geographical / logistical, legal, financial and cultural constraints.

The following may have influenced our findings; we only asked members of a the NSWG who attended the ECFS Conference and chose to be interviewed (interviews) or respond to the on-line questionnaire (questionnaires); the person answering the questionnaire was not always the person responsible for communicating positive NBS results; and we (the study authors) already have knowledge and a particular interest in CF NBS.

What's next?

Further research is needed to ensure information received is accurate, up-to-date and from the most appropriate person. Also, that all children are followed up in a timely manner to minimize potential negative outcomes for the child and family.

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