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Title

Communication of Carrier Status Information Following Universal Newborn Screening for Sickle Cell Disorders and Cystic Fibrosis: Qualitative Study of Experience and Practice

Agency NETSCC, HTA, NIHR Evaluation and Trials Coordinating Centre
Alpha House, University of Southampton Science Park, Southampton, SO16 7NS, United Kingdom;
Tel: +44 2380 595 586, Fax: +44 2380 595 639; hta@soton.ac.uk, www.hta.ac.uk

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Aim

To describe and explore current practice, methods, and experience of communicating carrier status information following newborn screening for cystic fibrosis (CF) and sickle cell (SC) disorders, to inform practice and further research.

Conclusions and results

Methods of communicating newborn carrier results vary across England. Parents' needs for timely and appropriate information may not be met. Respondents' experiences suggest a need for greater recognition of communication with individuals across a screening pathway, rather than as a discrete event. Methods for, and respondents' experiences of, communication of carrier results varied considerably within and between regions, and within and between SC and CF contexts. Approaches ranged from letter or telephone call, to in-person communication in a clinic or at home, with health professionals (eg, in hemoglobinopathy, CF, screening) or from community and primary care (eg, health visitors with SC carrier results). Health professionals identified pros and cons of different methods, preferring opportunity for face-to-face communication with parents where possible, particularly for CF carrier results. They were concerned by regional variations in protocols, the lack of availability of translated information on SC carrier results, and the feasibility of sustaining more specialist involvement at current levels, particularly for SC carriers. Parents were often poorly prepared for the possibility of a newborn carrier result. Some had felt overloaded by screening information received during pregnancy or prior to newborn screening, or found this information failed to meet their needs. Face-to-face communication of results was valued by parents of SC carriers and appeared particularly necessary for those without prior knowledge of SC carrier status, or where English was not their first language. Indirect communication of results by letter appeared effective and feasible for parents more aware of SC carrier status from antenatal or earlier experience, and where this communication contained an unambiguous opening statement emphasizing, "your child is not ill".

Recommendations

See Executive Summary link www.hta.ac.uk/project/1510.asp.

Methods

See Executive Summary link www.hta.ac.uk/project/1510.asp.

Further research/reviews required

Further research is needed to: (a) design and evaluate information for parents approached for a repeat blood spot in CF screening; (b) explore the value of refining prescreening information to better prepare parents for the possibility of carrier identification; (c) develop and evaluate the accessibility and acceptability of translated forms of standardized SC carrier result information; (d) prospectively study or audit practice with the further establishment of screening programs; (e) investigate how health professionals use and present information across the screening pathway; (f) develop and evaluate support and training for health professionals involved in screening to be able to communicate relevant information; (g) examine the use of differing mixed service models according to local contexts; (h) investigate parents' attitudes towards, access to, and experience of further carrier testing for themselves or their other children, and its impact on later reproductive decisions. (For further details see Executive Summary link www.hta.ac.uk/project/1510.asp.)

Written by Professor Joe Kai, University of Nottingham, NETSCC, United Kingdom

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