

DATA PAPER

Data: 'Initial Clinical Referral Standards after Newborn Screening for Congenital Hypothyroidism: Final Report of the UK Newborn Screening Programme Centre Expert Working Group and Systematic Evidence Review 2010-2011

Rachel L. Knowles¹, Freyja Olafsdottir²

¹ Clinical Research Fellow/Honorary Consultant, MRC Centre of Epidemiology for Child Health, UCL Institute of Child Health, London, UK

² Research Assistant (Summer Studentship), MRC Centre of Epidemiology for Child Health, UCL Institute of Child Health, London, UK

The multidisciplinary Expert Working Group was tasked with revising the existing standards of the UK NHS National Screening Programme for diagnosis and management of babies in whom congenital hypothyroidism (CHT) is suspected after newborn bloodspot screening. This report includes a systematic evidence review and account of the proceedings of the working group in key areas: screening test performance, referral pathways, diagnostic investigations, treatment and communication with parents. After public consultation, the recommendations were adopted as policy. This final report provides an evidence base for reviewing newborn screening for CHT in other populations and outlines a transparent consensus-based process for agreeing changes to screening standards and policy.

Keywords: congenital hypothyroidism, newborn bloodspot, newborn screening policy, systematic review, expert working group

Funding statement

The evidence review and working group were supported by funding from the UK NHS Newborn Screening Programme Centre.

(1) Overview

Context

Spatial coverage

United Kingdom

Temporal coverage

2010-2012

Species

Homo sapiens

(2) Methods

Steps

Systematic review: The systematic literature review included 115 published papers relevant to newborn screening for congenital hypothyroidism. Evidence summaries relating to each topic area were developed.

Expert Working Group: Members of the working group provided a consensus interpretation of the evidence relating to each standard. Recommendations for revising each standard were based on expert interpretation of the evidence and, if required, external experts were invited to present additional evidence.

Public consultation: A public consultation on the draft recommendations and revised standards was held in May/June 2012.

Published standards: A final revised set of standards was approved as screening policy and published in February 2013.

Sampling Strategy

Search strategies included the databases Embase, Medline, PsychInfo and Cochrane Trials Register, for the period up to June 2010, without imposing any language restrictions. Reference lists of retrieved papers were reviewed to identify additional papers.

Quality Control

Working Group recommendations were submitted to the UK National Screening Committee. A public consultation was held in May 2012. A publicly available consultation report is available from the UK Newborn Screening Programme¹.

Constraints

N/A

Privacy

Working group members, and any additional experts consulted, are named and their affiliations provided in the appendix to the report.

(3) Dataset Description**Object Name**

FINAL_REPORT_ICR_CHT_REVIEW_Jan 2013

Data Type

Systematic evidence review and report of expert working group proceedings.

Format Names and Versions

PDF, ODT

Creation Dates

1st January 2013

Dataset Creators

Rachel L Knowles, Freyja Olafsdottir

Repository Location

<http://dx.doi.org/10.5334/data.1373554611>

Publication Date

January 2013

Language

English

License

CC0

(4) Reuse potential

The systematic evidence review and report of the proceedings of the working group provides an evidence base for reviewing standards for clinical referral and investigation

after newborn screening for CHT in the UK, but would also be of relevance to other populations undertaking newborn bloodspot screening. It describes a transparent process for agreeing changes to screening standards and policy that is based on achieving cross-disciplinary understanding and consensus, and actively includes parents. The report is available to users and is intended to support the development of communication and a transparent methodology for achieving consensus and collaboration around newborn screening policy.

Acknowledgements

The expert working group included representatives of British Society for Endocrinology and Diabetes (BSPED), UK Newborn Screening Laboratory Network (UKNSLN) and UK Newborn Screening Programme Centre (UKNSPC). Expert working group members were: Dr Tim Cheetham (Chair), Ms Jacqui Adkins, Ms Lynn Booth, Professor John Gregory, Dr Jeremy Kirk, Dr Catherine Peters, Dr Melanie Downing, Dr Kate Hall, Dr Carol Evans, Ms Shirley Langham, Dr Laurence Abernethy, Mr Jez Jones, Dr Rachel Knowles, Ms Cathy Coppinger, Ms Radhika Rajani and Ms Brielle Woods. Additional contributions were sought from Ms Freyja Olafsdottir and Dr Tony Sirimanna. All members of the working group contributed significantly to the expert opinion statements, interpretation of the evidence, development of the standards and editing of the final report.

References

1. **UK Newborn Screening Programme Centre** 2012 Initial clinical referral (ICR) for congenital hypothyroidism (CHT) revised standards and guidelines consultation: 14th May 2012 to 15th June 2012. Accessed 10th February 2013 at <http://newbornbloodspot.screening.nhs.uk/icrchtconsultation>.

How to cite this article: Knowles, R L and Olafsdottir, F 2013 ata: 'Initial Clinical Referral Standards after Newborn Screening for Congenital Hypothyroidism: Final Report of the UK Newborn Screening Programme Centre Expert Working Group and Systematic Evidence Review 2010-2011. *Journal of Open Public Health Data* 1(1):e5, DOI: <http://dx.doi.org/10.5334/jophd.ae>

Published: 11 July 2013

Copyright: © 2013 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 3.0 Unported License (CC-BY 3.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/3.0/>.

