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Citation: Chudleigh, J. H. (2017). Information provision reduces parental anxiety. *Nursing Children & Young People*, 29(1), p. 19. doi: 10.7748/ncyp.29.1.19.s21

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Link to published version: <https://doi.org/10.7748/ncyp.29.1.19.s21>

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COMMENTARY

It is widely acknowledged that parents find the delivery of positive NBS results distressing and this appears to be largely influenced by information provision both at the time of screening and when the result is communicated to parents (Buchbinder and Timmermans 2012, Salm et al 2012, Chudleigh et al 2016).

Differences exist regarding how screening is offered to parents; in the UK, NBS is offered on a voluntary basis; parents are required to provide informed consent and therefore 'opt in' to the screening programme whereas in Switzerland (and in the United States of America (USA) (in all but one state) and Canada) an 'opt out' approach is taken. It could be argued that as parents in Switzerland (where this study was undertaken) are not required to provide informed consent for NBS, this could influence the information provided regarding the NBS process. However, this finding is not unique to this study and has also been found to be problematic in the UK where informed consent is required (Chudleigh et al 2016). Indeed, research has shown that even in the UK, parents often see NBS as a 'fait accompli' and as such do not consider that they have a choice to decline (Nicholls and Southern 2012) which may impact upon their experience when presented with a positive NBS results.

The findings of this study continue to support the notion that better information provision at all stages of the NBS process is required to reduce parental anxiety and distress and that this is something that needs to be addressed both nationally and internationally.

Balfour-Lynn IM. Newborn screening for cystic fibrosis: evidence for benefit. *Arch Dis Child* 2008;93:7–10.

Brice P, Jarrett J, Mugford M. Genetic screening for cystic fibrosis: an overview of the science and the economics. *J Cyst Fibros* 2007;6:255–61.

Buchbinder M, Timmermans S. Newborn screening for metabolic disorders: parental perceptions of the initial communication of results. *Clin Pediatr (Phila)* 2012 51(8):739–44.

Castellani C. Evidence for newborn screening for cystic fibrosis. *Paediatr Respir Rev* 2003;4:278–84.

Chudleigh J, Buckingham S, Dignan J, O'Driscoll S, Johnson K, Rees D, Wyatt H, Metcalfe A. Parents' Experiences of Receiving the Initial Positive Newborn Screening (NBS) Result for Cystic Fibrosis and Sickle Cell Disease. *J Genet Couns*. 2012 25:1215–1226

Nicholls, S. G., & Southern, K. W. (2014). Considering consent: a structural equation modelling analysis of factors influencing decisional quality when accepting newborn screening. *Journal of Inherited Metabolic Disease*, 37(2), 197–205. doi:10.1007/s10545-013-9651-x

Salm A, Yetter E, Tluczek A Informing parents about positive newborn screening results: Parents' recommendations *Journal of Child Health Care* 2012 16(4):367-81.

UK Newborn Screening Programme Centre. *Health Professional Handbook: A guide to newborn blood spot screening for healthcare professionals*. London: UK Newborn Screening Programme Centre, 2012.