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Title: Parents managing childhood long-term conditions: longitudinal research is needed on online forums as sources of peer-to-peer information

TITLE OF MANUSCRIPT: Carers' views of topical-corticosteroid use in childhood eczema: a qualitative study of online discussion forums

Information provision in health-care is being transformed by the internet, and online discussion forum websites are increasingly emerging as peer-to-peer health information-sharing platforms for parents and carers of children with long-term conditions [1, 2]. More than 8 out of 10 adults in Great Britain now use the internet daily or almost daily [3]. However, concerns are regularly expressed about the accuracy, reliability and trustworthiness of health information that is provided online, and whether harm to patients can be directly attributed to poor quality information found online [4].

In this issue of BJD, Teasdale et al [5] report on a qualitative study that sought to explore messages (and their resultant discussions) about topical-corticosteroids by parents/carers of children with eczema to two UK-based discussion forums; the first 100 search results for each forum were reviewed and analysed using inductive thematic analysis. Three themes emerged: (1) Diverse beliefs about the use of topical-corticosteroids; (2) uncertainty and confusion about using/applying topical-corticosteroids; and (3) seeking to resolve conflicting advice received offline and advice on navigating health services. Concerns were expressed about short-term, rebound, withdrawal and transient effects of cortico-steroids, but users also appeared to value the social support available on the forums and the scope for accessing the experiential knowledge of 'expert parents'. However, experiences of conflicting advice also contributed to forum users' accounts of uncertainty and caution around topical-corticosteroid use, and seemed to create doubts about the trustworthiness of some professional advice.

The authors concluded that the confusion expressed online by parents indicates a need for clear signposting of parents to consistent and reliable advice about topical-corticosteroids. Otherwise parents are at risk of finding and acting upon advice that has a potentially negative impact on the child's management. This finding is consistent with the results of a recent systematic review on antecedents of trust in health information websites [4]. The review authors note that trust is supposed to be a dynamic process which can be built, maintained, and decline over time, so they recommend a longitudinal study on evaluating trust in health websites to address some of the very concerns reported by Teasdale et al.

Therefore, Teasdale et al's conclusion that further research is needed to find effective ways of communicating with parents/carers is important. Furthermore, the need to develop resources to support patients after consultations with professionals is entirely consistent with this new emerging evidence. Moreover, Teasdale et al's qualitative study could pave the way for a longitudinal study that forms the modelling stage of preliminary development and feasibility testing of a resource (or complex

intervention) to support parents if questions arise after a consultation. This could be a precursor to a full randomised controlled trial thereby using a rigorous and phased approach to intervention development and evaluation[6, 7].

REFERENCES:

1. Cole, J., C. Watkins, and D. Kleine, Health Advice from Internet Discussion Forums: How Bad Is Dangerous? *J Med Internet Res*, 2016. **18**(1): p. e4.
2. Kirk, S. and L. Milnes, An exploration of how young people and parents use online support in the context of living with cystic fibrosis. *Health Expect*, 2016. **19**(2): p. 309-21.
3. ONS, Internet access – households and individuals: 2016. 2016: London.
4. Kim, Y., Trust in health information websites: A systematic literature review on the antecedents of trust. *Health Informatics Journal*, 2016. **22**(2): p. 355-369.
5. Teasdale, E., I. Muller, and M. Santer, Carers' views of topical-corticosteroid use in childhood eczema: a qualitative study of online discussion forums. *British Journal of Dermatology*, 2016.
6. MRC, Developing and Evaluating Complex Interventions: New Guidance. 2008.
7. Richards, D. and I. Hallberg, eds. *Complex Interventions in Health: An Overview of Research Methods*. 2015, Routledge: London.