

## Correspondence

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### Cost of commercial protectionism in child health research

As someone with a background in both public health research and homeless services, I was recently approached by a group of voluntary agencies working with homeless families to assist them in conducting a research project to investigate the mental and physical health status of children passing through their services. The personnel involved were alarmed by what they saw as the largely undiagnosed, unmeasured and unmet needs the children presented. As part of my public service obligation as an academic, and having an interest in the topic, I readily agreed to help on a pro bono basis.

Attempting to identify a useful health measure threw up the routine issues of a lack of standardisation in assessment, a lack of national normative data, and the dearth of child health measures covering both mental and physical health. However, after an extensive search, two potential measures were identified. The first was the 50-item Parent Form of the Child Health Questionnaire (the CHQ-PF50),<sup>1</sup> which is suitable for older children, and the second was the Infant/Toddler Quality of Life Questionnaire (ITQOL)<sup>2</sup> for younger children.

This project was launched in response to real children's needs in the Irish context of voluntary agencies operating on shoe-string budgets, in an era of tightening budgets, a reduction in a government expenditure of over €6 billion in the next financial year, and a bail out from the International Monetary Fund and European Union.

The next barrier was the fee for the use of the proposed measures. Although some may accept the need to charge fees as a commercial reality, it could equally be argued that a wider appraisal, incorporating good publicity, exposure, a worthy cause, and publications/citations may be equally valuable in the long term.

However, putting the issues of fees aside, two points in the proposed licence agreement with the licencing company, HealthActCHQ, were very disturbing. The first prohibited the development of the measures. HealthActCHQ stated that all 'developmental work is undertaken exclusively by our scientific team'. The second issue of concern was the prohibition on developing normative data for Ireland. This restriction was explicitly stated: 'HealthActCHQ does not allow anyone to undertake iterative work, such as the development of normative data'. It should be noted that no Irish normative data for either of these measures are available and, as far as can be ascertained, there is no 'work in progress'.

It could be conceivable that through this commercial protectionism quality may be sacrificed for profit in the field of

child health research. Companies in the psychometric and child health field are possibly stifling developments and improvements for commercial reasons. Furthermore, attempts at precision to overcome geographical, national, cultural, linguistic and temporal differences in normative scores are ignored and sacrificed.

Academics and clinicians need to be wary of health measures that may be suboptimal as a result of blatant commercial protectionism. Peer review and continued development are quality hallmarks that should not be swept aside lightly. Academics and clinicians need to cooperate to develop open-access<sup>3</sup> standardised measures of child health status and matching normative data. Such a united focus would inevitably benefit all concerned, particularly those most in need.

- 1 Landgraf JM, Abetz L, Ware JE. *The CHQ: A User's Manual*. The Health Institute, 1996.
- 2 Landgraf JM, Abetz L. *The Infant/Toddler Quality of Life Questionnaire: Conceptual Framework, Logic, Content, and Preliminary Psychometric Results. Final Report to Schering-Plough Laboratories and Health Technology Associates*. New England Medical Center, 1994.
- 3 Evans C, Connell J, Barkham M, Margison F, McGrath G, Mellor-Clark J, et al. A copyleft (free) self-report measure for psychological therapies: psychometric properties and utility of the CORE-OM. *J Affect Disord* 2002; **68**: 109–110.

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**Author's reply:** HealthActCHQ business is the development and the licensing of functional outcomes and quality-of-life surveys. HealthActCHQ is a privately owned, for-profit, scientific business. Since 1995, the company has been providing limited-use licenses for researchers. For more than 18 years, HealthActCHQ has developed and scientifically enhanced their total body of survey measurement work – including the Child Health Questionnaire (CHQ) and the Infant/Toddler Quality of Life Questionnaire (ITQOL). The company's surveys have not been developed with government grants, educational endowments or any other public funds.

As a private company, we self-fund all survey development, continuing support and ongoing scientific research. All surveys, scoring and normative data are proprietary and confidential information of HealthActCHQ, and are protected under the US Copyright Act and are protected in Ireland under one or more international treaties or conventions. The surveys, scoring algorithms and normative data are not in the public domain. Further developmental work on the company's intellectual property assets is the fiduciary obligation, role and right of our company's internal scientific development staff.

The company's website (www.healthactchq.com) openly provides detailed information for review prior to inquiry for registration on its licensing model and the terms and conditions for licensure and use. Licenses are granted to academic researchers, public health organisations, medical practice settings, clinical trials and others on the terms as presented at the website.

There are more than 350 international peer-reviewed manuscripts on the CHQ and the ITQOL presented on our website bibliography.

Declaration of interest

HealthActCHQ is the developer, owner and licensor of the CHQ and ITQOL as well as other patient-reported outcomes surveys,