



Evaluation of a cartoon-based knowledge dissemination intervention on scientific and ethical challenges raised by nutrigenomics/nutrigenetics research



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ABSTRACT

Context: The push for knowledge translation on the part of health research funding agencies is significant in Canada, and many strategies have been adopted to promote the conversion of knowledge into action. In recent years, an increasing number of health researchers have been studying arts-based interventions to transform knowledge into action. This article reports on the results of an online questionnaire aimed at evaluating the effectiveness of a knowledge dissemination intervention (KDI) conveying findings from a study on the scientific and ethical challenges raised by nutrigenomics–nutrigenetics (NGx) research. The KDI was based on the use of four Web pages combining original, interactive cartoon-like illustrations accompanied by text to disseminate findings to Canadian Research Ethics Boards members, as well as to NGx researchers and researchers in ethics worldwide.

Methods: Between May and October 2012, the links to the Web pages were sent in a personal email to target audience members, one thematic Web page at a time. On each thematic Web page, members of the target audience were invited to answer nine evaluation questions assessing the effectiveness of the KDI on four criteria, (i) acquisition of knowledge; (ii) change in initial understanding; (iii) generation of questions from the findings; and (iv) intent to change own practice.

Findings: Response rate was low; results indicate that: (i) content of the four Web pages did not bring new knowledge to a majority of the respondents, (ii) initial understanding of the findings did not change for a majority of NGx researchers and a minority of ethics respondents, (iii) although the KDI did raise questions for respondents, it did not move them to change their practice.

Conclusions: While target end-users may not feel that they actually learned from the KDI, it seems that the findings conveyed encouraged reflection and raised useful and valuable questions for them. Moreover, the evaluation of the KDI proved to be useful to gain knowledge about our target audiences' views since respondents' comments allowed us to improve our understanding of the disseminated knowledge as well as to modify (and hopefully improve) the content of the Web pages used for dissemination.

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1. Introduction

Increasingly, health researchers are required by funding agencies to develop knowledge translation (KT) plans that include activities meant to disseminate their research findings among

various audiences. The Canadian Institutes of Health Research (CIHR), the major funding agency for health research in Canada, has proposed the most widely used definition for KT: “Knowledge translation is a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system.”² There are many ways to put research into practice and many KT strategies have been proposed to increase knowledge, change attitudes or practice (Scott et al., 2012) in clinical, government and

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² About knowledge translation & commercialization – CIHR (accessed 19.11.13).

research settings. In the last few years, the arts have emerged as an innovative avenue for disseminating scholarly findings (Bombard, Cox, & Semaka, 2011; Boxall & Ralph, 2009; Lafrenière & Cox, 2012a,b). If photographs (Lafrenière, Hurlimann, Menuz, & Godard, 2012; Teti, Murray, Johnson, & Binson, 2012; Vaughn, Rojas-Guyler, & Howell, 2008), and, to a lesser extent, films and videos (Parsons & Lavery, 2012; Rich, Lamola, & Woods, 2006; Shapiro, Tomasa, & Koff, 2009) have been explored as a visual way of presenting study results, cartoons and other forms of drawings have rarely been used for disseminating health research findings (Bartlett, 2012; Guillemin, 2004).

The main objective of this article is to present the results of the evaluation of a knowledge dissemination intervention (hereafter: “KDI”) based on the use of cartoon-like visuals, accompanied by text, and aimed at disseminating the results of a study on the scientific and ethical challenges raised by nutrigenomics-nutrigenetics (hereafter referred to as “NGx”).

2. Background

NGx – a field of research that studies the interactions between genome/gene(s) and nutrition, and their impact on health and well-being³ – has stimulated great expectations for future beneficial applications in public health and individuals. For instance, NGx research anticipates the prevention of chronic diseases, such as cancer and diabetes, through personalized dietary interventions, engineered/modified foods that respond to consumers’ specific genetic characteristics, and contribution to better public health (Godard and Hurlimann, 2009; Ronteltap & van Trijp, 2007). Yet, the potential achievability of such promises is not without socio-ethical considerations that challenge NGx development and implementation. Studying ethical issues relevant to personalized health interventions, spanning from clinical discoveries/innovation to publication/translation of clinical -omics research data is crucial because it can influence the development of personalized health interventions and help avoid predictable pitfalls, thus ensuring an effective and ethical application of NGx in the laboratory, in the clinic and in the evidence-based development of science policy. For that purpose, the OMICS-ETHICS Research Group⁴ based at the University of Montreal, Canada, conducted a research project aimed at laying an empirical foundation that could discern and anticipate the socio-ethical issues associated with NGx research and its potential applications (hereafter “NGx project”).⁵ In the first phase of this project, an extensive analysis of 173 NGx clinical studies published between 1998 and 2007 inclusively was carried out.⁶ It highlighted both scientific challenges and significant ethical concerns raised by the geographical location of NGx clinical studies, by the selection of participants in NGx clinical studies, by the methodological limitations encountered in NGx research, as well as by the publication of study results and their interpretation. These study results were published in peer-reviewed journals (Hurlimann, Stenne, Menuz, & Godard, 2011; Hurlimann et al., 2014; Stenne, Hurlimann, & Godard, 2012; Stenne, Hurlimann, & Godard, 2013) and are presented and summarized in the final report of the project, accessible online.⁷ The findings on which this article focuses are also reported in the next section.

³ See <http://www.omics-ethics.org/en/what-is-nutrigenomics> (accessed 18.4.13).

⁴ See information about the OMICS-ETHICS Research Group on their Web site: <http://www.omics-ethics.org/en> (accessed 21.11.13).

⁵ See <http://omics-ethics.org/en/research-projects-nutrigenomics> (accessed 18.4.13).

⁶ The methodology used is available online: <http://www.omics-ethics.org/docs/news/Methodo-NGx-Project-Omics-Ethics.pdf> (accessed 18.4.13).

⁷ See final report available online: <http://omics-ethics.org/en/NGx-research-project-results> (accessed 19.11.13).

In order to disseminate these findings beyond the usual channels (i.e., scientific literature and conferences), a sub-study of the NGx project (hereafter referred to as “KDI study”) was developed and aimed at designing, implementing and evaluating a knowledge dissemination intervention (KDI) among researchers in NGx and in ethics, as well as members of research ethics boards/institutional research boards (REBs/IRBs). The present article describes the development of this KDI and focuses on the results of the study aimed at evaluating its effectiveness.

3. Development of the KDI and methods

3.1. Literature review

Prior to developing the knowledge dissemination intervention (KDI), the members of the OMICS-ETHICS research group performed a literature review (Lafrenière, Menuz, Hurlimann, & Godard, 2013) to gain information on the types of KDIs used in applied research, and the evaluation of their effectiveness. It shed light on the variety of interventions, contexts, and actors involved, and highlighted the complexity of implementing KDIs. No articles described a KDI with research findings and target audiences similar to those in this KDI study. Therefore, the review did not provide information that could be transformed instantly into a readily implementable KDI for the communication of the findings of the NGx project.

3.2. Knowledge to be disseminated (message)

As mentioned above, a detailed content analysis of 173 NGx clinical studies was performed in the NGx project. Various data were extracted from these publications, such as participants’ geographical location; participants’ particulars, such as race, ethnicity, origin, nationality, ancestry, age, sex, comorbidities, and any other available data linked to participants’ description, as well as any exclusion and inclusion criteria reported by the authors. The following elements were also extracted from the publications of our sample: all authors’ statements or comments about the potential or actual impact of genetic variations linked to ethnicity, and all limitations of the study results explicitly acknowledged and reported by the authors.⁸ While the results of this analysis do not question the validity or relevance of NGx research, they deserved wide dissemination among stakeholders in the field of NGx, as they raise both scientific and ethical concerns, in four pivotal themes:

1. A majority of the NGx clinical studies in our sample focus on “white” or “Caucasian” populations and that there is little coherence in the way the terms race/ethnicity/ancestry/origin and even nationality are used to describe sample populations. Information about the participants’ origin could be found in 124 publications (72%), thus it could not be determined for 49 studies (28%) of our sample. Yet, ethnicity matters in NGx research as it is of the utmost importance to consider the influence of acculturation on diet and health, and the impact of genetic admixture in populations and genomic variability on research results. In such circumstances, can it be inferred to what populations study findings can apply if the ethnicity of participants is not explicitly reported in publications? Moreover, what can be the impact of a lack of representation of ethnic minorities in NGx clinical research, in terms of fairness and equity? (<http://omics-ethics.org/en/nutrigenomics-ethnicity>; accessed April 2013)

⁸ A complete description of the methodology used is available online: <http://www.omics-ethics.org/docs/news/Methodo-NGx-Project-Omics-Ethics.pdf> (accessed 18.4.13).

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