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Communication in a Human biomonitoring study: Focus group work, public engagement and lessons learnt in 17 European countries

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ABSTRACT

A communication strategy was developed by The Consortium to Perform Human Biomonitoring on a European Scale (COPHES), as part of its objectives to develop a framework and protocols to enable the collection of comparable human biomonitoring data throughout Europe. The framework and protocols were tested in the pilot study DEMOCOPHES (Demonstration of a study to Coordinate and Perform Human biomonitoring on a European Scale). The aims of the communication strategy were to raise

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awareness of human biomonitoring, encourage participation in the study and to communicate the study results and their public health significance. It identified the audiences and key messages, documented the procedure for dissemination of results and was updated as the project progressed. A communication plan listed the tools and materials such as press releases, flyers, recruitment letters and information leaflets required for each audience with a time frame for releasing them. Public insight research was used to evaluate the recruitment material, and the feedback was used to improve the documents. Dissemination of results was coordinated in a step by step approach by the participating countries within DEMOCOPHES, taking into account specific national messages according to the needs of each country. Participants received individual results, unless they refused to be informed, along with guidance on what the results meant. The aggregate results and policy recommendations were then communicated to the general public and stakeholders, followed by dissemination at European level. Several lessons were learnt that may assist other future human biomonitoring studies. Recruitment took longer than anticipated and so social scientists, to help with community engagement, should be part of the research team from the start. As a European study, involving multiple countries, additional considerations were needed for the numerous organisations, different languages, cultures, policies and priorities. Therefore, communication documents should be seen as templates with essential information clearly indicated and the option for each country to tailor the material to reflect these differences. Future studies should consider setting up multidisciplinary networks of medical professionals and communication experts, and holding training workshops to discuss the interpretation of results and risk communication. Publicity and wide dissemination of the results helped to raise awareness of human biomonitoring to the general public, policy makers and other key stakeholders. Effective and timely communication, at all stages of a study, is essential if the potential of human biomonitoring research to improve public health is to be realised.

1. Introduction

Human biomonitoring (HBM) studies can be used to assess exposure to existing and emerging environmental substances, and the results can help make informed decisions on health protection. Effective communication in HBM is not only important for dissemination of results; it can also help to achieve good participation rates and increase the study participants' agreement, trust and confidence in the field workers, which can help to ensure good-quality data (Cargo and Mercer, 2008; Keune et al., 2008; O'Fallon and Dearry, 2002). Therefore, it is vital that communication strategies are developed right from the start of a HBM study and allowed to evolve as the study continues (Sepai et al., 2008).

Traditionally, communication between scientists and the public has been a one-way process, but this does not take into account the public's perception and understanding nor does it involve local stakeholders in the decision-making process. A two-way approach is followed in Flanders, Belgium, where risk perception and increased dialogue with local stakeholders are incorporated into the HBM campaign (Keune et al., 2008). Community-based participatory research, in which the community is involved from the start with the design of the study, interpretation of results and consequent action (Balazs and Morello-Frosch, 2013), takes this a step further. Benefits of this approach include community trust in the researchers, increased use and relevance of the data and improved dissemination (Balazs and Morello-Frosch, 2013; O'Fallon and Dearry, 2002). This approach has been successfully applied in studies where specific pollution is a concern; HBM research in Ohio after perfluorooctanoate contamination of a residential water supply raised community awareness and modified individual and stakeholder behaviours (Emmett et al., 2009). It has also been applied in general environment health research; the Northern California Household Exposure Study found the approach increased environmental health literacy and generated individual and policy action to protect health (Brown et al., 2012).

Communication of HBM results to participants varies by study but traditionally the 'clinical ethics' approach has been used. The Canadian clinic-recruitment based 'Maternal–Infant Research on Environmental Chemicals' study (Haines et al., 2011) and national HBM studies in Portugal (Reis et al., 2008) have used this approach in which just the aggregate results are provided or individual results are given but only when health-based guidance values and interventions are available (Morello-Frosch et al., 2009). Other studies have moved towards a more open approach providing both individual and aggregate levels results, even if there are no clear health guidelines. Examples include the household recruitment-based Canadian Health Measures Survey (Haines et al., 2011), the Flemish HBM program (Schoeters et al., 2012) and the German Environmental Survey (Schulz et al., 2007).

Communicating individual results when there is a lack of health guidance values to interpret the data may empower individuals or could cause worry and concern (Brody et al., 2007). Washburn's experience from interviewing HBM study participants suggested that frustration due to an individual's limited ability to take action to protect themselves from future exposures is also an issue (Washburn, 2014). Individuals may interpret the results themselves and take inappropriate action, for example; detection of chemicals in breast milk may cause mothers to stop breast-feeding. Arendt discussed how this can occur if the communication strategy of such HBM studies is not in line with public health messages for breast milk studies (Arendt, 2008). A discussion with scientists and local stakeholders in Belgium for the centre of Expertise for Environment and Health concluded that transparency should be given priority over a concern that individuals may interpret the results differently to the scientists (Keune et al., 2008).

However, such research needs to consider carefully how information is communicated and what public health messages are used (Arendt, 2008). Wu et al. (2009) evaluated the impact of participating in a HBM study measuring polybrominated diphenyl ethers in breast milk, on breast feeding practices. The participants were provided with clear information about the benefits of breastfeeding and careful consideration was given to the provision of the individual results (by telephone). Follow up found that participants who were concerned about the results were reassured by the study information, the personal communication and the message 'breastfeeding is best'. Researchers need to be clear about the scientific uncertainties, provide information on how to reduce exposures and put the results into context, for example, by making comparisons with other populations (Brody et al., 2014).

A communication strategy, to take into account these issues, was included in the framework and protocols developed by The Consortium to Perform Human Biomonitoring on a European Scale