Cross-Mediterranean Environment and Health Network

CROME-LIFE

Deliverable B.3.2

Communication plan of the human biomonitoring campaign results

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Action: B.3 Targeted measurement campaigns to fill the data gaps

TASK: 3.1.2 HBM campaign design

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Introduction

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, HBM 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 , 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, 2014). 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 breastfeeding. 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 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' (Wu et al. 2009). 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 (COPHES) to enable the collection of comparable HBM data throughout Europe. The framework and the protocols were tested in DEMOCOPHES (Demonstration of a study to Coordinate and Perform Human biomonitoring on a European Scale), a pilot study in which 17 European countries assessed exposure to cadmium, environmental tobacco smoke, phthalates and mercury in children and their mothers by sampling urine and hair (Joas et al. 2012, Excley et al. 2014). In CROME similar approach is to be undertaken in the Cross-Mediterranean case study and national case studies.

The Communication and dissemination actions in CROME are elaborated in Action D.1 with a wider scope and stakeholder participation. The communication strategy described in this deliverable is primarily intended for communication strategy with the study population involved in HBM campaigns of CROME. The objectives of the communication strategy at this level are: 1) to promote public awareness of human biomonitoring, 2) to enhance recruitment and informed consent of study population in CROME, and 3) to report individual and collective results and explain their public health significance.

The summary objectives and corresponding communication materials as developed and tested in other European projects are summarized in Table 1.

Table 1: The main communication tools, materials and activities developed to address the communication objectives of the project (adopted from Excley et al., 2014), which are also applicable for CROME.

Communication objective	Tools/materials/activities
1) to promote public awareness of human biomonitoring	Press release Articles in national and regional newspapers Flyers, posters, banners Study information leaflets for the public, Newsletters EU and National Websites A TV documentary
2) to enhance recruitment and informed consent of study population	Invitation letters and study information Information meetings study population Consent forms and reply cards Public insight work
3) to report individual and collective results and explain their significance to public health	Guidance on communicating results for participating countries A professional network to discuss interpretation of the results and communication strategies Study participants results letter Chemical information factsheets Meetings with study participants Layman's study report
4) ensure transparency and openness by informing diverse stakeholders about aggregate results across Europe and within participant countries 5) to safeguard translation of results into precautionary and preventative policy	Technical study report Policy information sheets and meetings with policy officials Study information leaflets for general practitioners Scientific publications and presentations at scientific congresses Newsletters Press releases Articles in national and regional press

The communication materials to be produced in CROME to communicate directly with study population will include the following:

1. At the start of the study – recruitment stage

1.1. Policy cornerstone paper

This provides a description of the project and what the study will mean for the country. Each participating country is required to tailor the cornerstone paper to their country's specific needs and current policies on HBM.

1.2. The invitation letter for the study participant

Potential study subjects will be sent an invitation letter to join the study along with an information leaflet and a reply card. The invitation letter contains at least the following details:

- Description of the study
- Eligibility criteria
- Purpose clearly stated
- The benefits and risks
- Participating country's specific details (the contact name and the institution)
- Details on how the study leader obtained the potential participant's contact information
- What taking part involves
- What happens to the results

1.3. The information leaflet

The information leaflet gives a brief summary of the study and its aims, clearly outlining the entire process in a language accessible for a non-expert audience. It also outlines what participation means in practice; how long participation takes, where it takes place and what it involves. The following list is not exhaustive but gives an idea of the main topics covered:

- Explain that participation is always voluntary and that participants can withdraw at any time
- Outline the nature and aims of the research
- Explain exactly what participation means in practice (when, where, who, what)
- Outline clearly the inclusion and exclusion criteria for participating in the study
- Outline any risks, inconvenience or discomfort that could reasonably be expected to result from the study
- Describe the benefits for participants (if relevant, as there might not be any direct benefits for the participant)
- Consent of the ethics committee

- Explain how privacy and confidentiality will be maintained

1.4. The reply card and the reminder letter

If potential participants have not returned the reply card within 25 days before the start of the field work a reminder letter is sent. This asks participants to return the reply card even if they are not interested in taking part in the study. Those who respond but do not want to take part will be asked the non-responder questionnaire. This will assist with assessing potential selection bias. Once a reply card is received the participant is contacted to check they meet the inclusion criteria and, if so, to arrange a time and date for the visit.

2. During the study – study conduct

2.1. The appointment letter (2nd letter) and informed consent

Participants who meet the inclusion criteria will then be sent an Appointment (2nd) letter to confirm the time and date of visit and two copies of the informed consent form are enclosed. Participants are asked to sign one copy of the consent form and return to the study centre.

2.2. The letter of thanks

Potential participants who do not meet the inclusion criteria are sent a letter of thanks for taking an interest in the study.

2.3. The pre-visit letter (3rd letter) and instruction leaflet for sampling

This reminds participants of the time and date of the appointment and to return a signed consent form if they haven't already. The letter states that participants can ask questions and sign the consent at the visit before the interview if they have not sent the consent form back in time. The interview cannot proceed without a signed consent form. Enclosed with the letter information on sampling urine, if relevant.

2.4. The withdrawal form

A form has been prepared for any study subjects who decide that they wish to withdraw from the study. Study participants can withdraw at any time from the study and asked to confirm their withdrawal with a signature. Two options are provided for withdrawal and are shown below;

- "No further contact but my samples can be used": This means that CROME would no longer contact you directly, but would still have your permission to retain and use information and samples provided previously.
- "No further contact and my samples cannot be used": This means that, in addition to no longer contacting you or obtaining further information about you, any information and samples collected previously would no longer be available to researchers. CROME would destroy your stored samples and would only hold your information for archival audit

purposes. Your signed consent and withdrawal would be kept as a record of your wishes. Such a withdrawal would prevent information about you from contributing to further analyses.

3. After sampling and analysis – communication of the results

3.1. The results letter

Results will be sent to the study participants (individual results and collective results, following on request and the wish of each participant). It is important to highlight to participants that for some of the chemicals we will be able to describe what the levels measured in their biological samples means for them. Whereas for other chemicals, we do not have any information on whether the levels have any relation with possible health effects, therefore we will only be able to tell them the levels and compare these levels to the collective results.

In the letter, the study participants will be reminded as to what will happen to the rest of the samples i.e. samples will be stored for 10 years in a Biobank and may be used for further analyses. This has previously been stated in the information leaflet and consent form.

3.2. The chemical factsheets

The factsheets will be sent out with the result letter. They have been prepared to provide study participants with more information on the chemicals tested. The sheets give a brief description of the chemical, where it occurs, likely sources of exposures, chronic toxicity effects, HBM of the chemical and risk management options. These will also be made available in advance on the CROME website and should be translated and posted on each country's national website.

3.3. The policy cornerstone paper – Aggregated results

To allow policy comments and reactions, policy makers must be informed of the messages that will be released so that they can prepare a response, if required. A cornerstone paper/factsheet for policy makers of the results will be prepared once the results have been analyzed. This will provide a description of the project and provide details on the results of the study. Each participating country is required to tailor the cornerstone paper to their country's policies on HBM.

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