HBM4EU project

Communication of HBM results to groups and individuals

Paul T.J. Scheepers PhD

Task leader WP2.5 training

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Communication of HBM results

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- A communication plan should be ready before starting the HBM campaign
- The communication procedures and materials should be made available when the study protocol is evaluated for ethics approval
- Note that children should be able to opt out when they turn 18.
- The informed consent should cover the broader use of data in the context of HBM4EU, including use of HBM data for IPCHEM.

Communication of HBM results *Communication plan*

- Explain how and when the results of the study will be made available
- Results on a group level should be communicated without explicit information that might point to an individual by name, street address or any other (indirect source of) information.
- Who will be the sender? Who is the receiving party (e.g. in the case of adolescents)
- Be aware that in small groups individuals may still be(come) identifiable (indirectly by a combinations of certain characteristics)

Communication of HBM results *Communication plan*

- Even if you are reporting on biomarkers of exposure (only) many subjects may still perceive a lab result as health-related information.
- Any outcome may have more impact if the study subject is a child or otherwise vulnerable individual
- Be prepared to refer a study participant to a physician if there are questions related to the personal/medical situation, e.g. concerning pregnancy.

Communication of HBM results

Message

- Confirm what is already known and also address any questionable information is released through social media, e.g. regarding:
  - Hazard classification of a chemical
  - Interpretation of risk level that is unrealistic
- What context is available for reporting of the biomarker of interest:
  - Background in the population as a reference
  - Guidance values for the general population
  - Guidance values for the worker's population
- Do not be afraid to address the fact that there is uncertainty or even a gap in knowledge

Communication of HBM results

Message

- What are the possible causes and consequences of an enhanced biomarker outcome?
- What can the subject himself/herself do about it? Also if nothing can be done about it, this should be highlighted.
- Address the problem that an individual outcome cannot be translated to a risk.
- Only in limited cases a group level could be put in perspective if the group can (to some extent) be compared to a population that was earlier studied in a sound epidemiological design

Use Supporting information such as

- Graphic
- Animation
- Video message
- Podcast

Communication of HBM results

Group

What are the proper channels to communicate

- Personalized written information
- Closed group meeting (for participants only)
- Refer to the possibility of an individual consultation as an add-on if this should be needed, also at a later stage (e.g. for participating children)

Communication of HBM results

Individual

- It is a good practice to involve an independent physician available to discuss concerns that the subject (or his/her parent/caretaker) does not want to discuss with the researcher. This physician should accept to take this role and be well-informed about the study.

Communication of HBM results

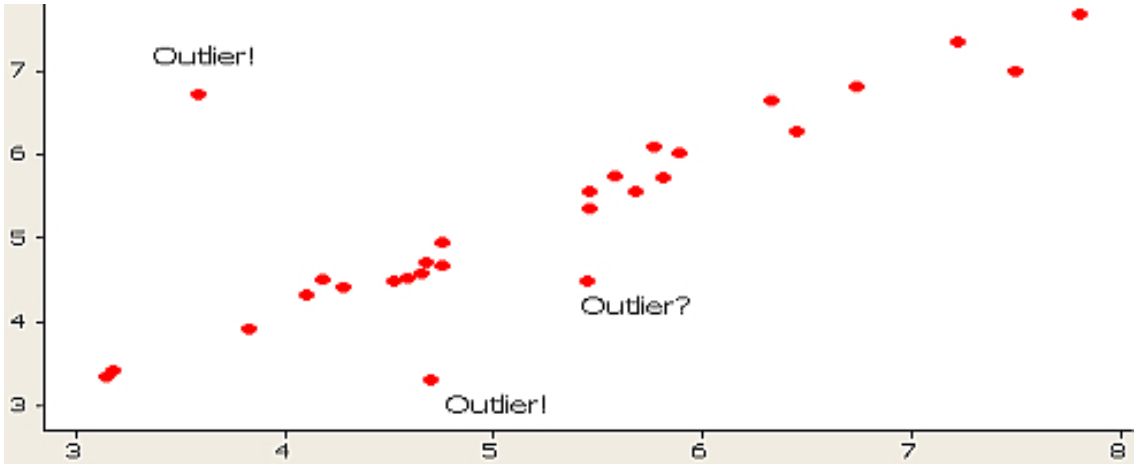
Individual

- Consider to ask the subject if he/she wants to have access to his/her own data as part of the informed consent.
- Consider to ask the subject if he/she agrees that individual HBM data are made available to the general practitioner
- Note that a finding may be(come) relevant if it indicates a health problem such as a too high urinary creatinine as an indication of kidney damage. You need the consent of the study subject if you want to inform the subject's physician.

Communication of HBM results

Individual

- Would be good to think over a scenario where individuals have (expectedly or unexpectedly) a higher value.
- What if the individual result is an outlier. Is there a contingency plan, e.g. an offer to repeat collect and analyse a follow-up sample.



Take home

Good to agree on a communication plan from the start

Define the communication process and the message for each scenario

Do not be afraid to name uncertainties and unknowns

Provide additional personal counselling if needed

Contacts

paul.scheepers@radboudumc.nl

HBM4EUtraining.hev@radboudumc.nl

Speaker's information

Paul T.J. Scheepers PhD works as associate professor at the Radboudumc, Nijmegen, The Netherlands. He received training in toxicology and occupational hygiene. In HBM4EU he is responsible for training activities as task leader in WP2. He is a member of the ethics board in WP1.

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