# The importance of communication in the success of a large biomonitoring study: example of the French Dioxin and Incinerators Study

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# Abstract

The French Dioxin and Incinerators Study was designed to estimate whether serum dioxin levels were higher in people living exposed or non-exposed to waste incinerators emissions. The study involved 1030 adults (30-65 years old) selected through a stratified two stage random sampling, from 8 locations in France. Serum analyses of PCDDs, PCDFs and PCBs were performed, and questionnaire data were collected through questionnaires.

In such a study, the communication between the population and the investigators is a crucial point. Difficulties arose principally during the recruitment (complexity of the criteria for inclusion and exclusion), the blood collection and the interviews (the need for a large volume of blood required and time-consuming questionnaires), and the communication of final results (impossibility of giving a health interpretation of the dioxin serum levels). A good communication was required to face these obstacles. Early presentation of the objectives of the study and of the protocol was a key point in obtaining a favourable involvement of the population.

# Introduction

The French Dioxin and Incinerators Study was designed to estimate whether serum dioxin levels were higher in people living exposed to waste incinerators emissions, compared to referent people. The influence on the serum levels of behavioural factors such as local food consumption was also investigated.

The study involved 1030 adults (30-65 years old) selected through a stratified two stage random sampling, from eight locations in France. Serum analyses of PCDDs, PCDFs and PCBs were performed, and questionnaire data were collected<sup>1</sup>.

In such a study, the communication between the population and the investigators is a crucial point. Three steps are especially sensitive:

- the recruitment of the participants
- the blood collection and the interviews
- the communication of the results

This paper analyses the main difficulties encountered at each of these steps.

# **Recruitment of participants**

Prior to the recruitment, the study was presented to the local authorities: the prefect (representing the state) and the mayors of the 8 locations selected for the study. The authorisation of these local authorities was indeed an asset before launching the study. Moreover, local authorities were a precious help to transfer information to the general population. They also collaborated providing:

- the population listing (voter list) on which the sampling was done

- access to rooms for public meetings, blood collections and interviews
- an interface with local media

Public meetings were organised to present the study. The participation to such meeting was limited, especially in the locations non-exposed to a waste incinerator but local press contributed to the dissemination of the information with papers published after these meetings. Documentation was also edited on the web site of the National Institute for Public Health Surveillance: short brochures, fact sheets and FAQ to answer the main questions on dioxins.

The sampling was based on voters' lists of the cities, completed by the list of the main phone operator, France Telecom, which provided the phone number of its customers. During the first phone contact,

- the study was briefly presented,
- the people belonging to the same household were identified,
- the people respecting the criteria for inclusion in each household were identified: age between 30 and 65 years old, time of residence in the area above 10 years, without occupational exposure, without a significant weight loss in the past 6 months, no breastfeeding in the past 15 years, substantial consumption of locally produced food or no consumption of locally produced food.

The objective of this phone call was to establish a sampling base of eligible households, with the names and surnames of the members falling within the criteria, and an indication of their consumption of locally produced food (to allow a stratified-sampling on this criterion). Due to the large number of phone calls required (11 507 phone calls were made), the work was performed by a call centre. Despite the training of its employees, the task was sensitive and the phone calls were not always positively perceived, even if the calls were not too long. Moreover, interviewed people did not always give information on the other members of their household. The consequence was that some of the people sampled did not respect the criteria for inclusion.

All this shows the importance of doing the maximum to optimise the participation to the study: involvement of local authorities, documentation available at the city hall and on the Internet, public meetings, and communication through the media... However, the first phone contact remains the key step to obtain a good sampling base and a good participation rate. The call has to be done by trained professionals. The first phone call is the most direct way to contact the people. A poorly handled phone contact cannot be counterbalanced by the other communication means subsequently available:

- letters to the people sampled, including a presentation of the study
- other phone calls for appointments and advice on the blood collection.

# **Blood collection and interviews**

The minimal time required for the blood collection and the completion of several questionnaires was 2 hours. The participants were invited to a public room close from their residence, between 7 a.m. and 10.30 a.m. A maximum of 30 people was interviewed per day. They were asked to follow these steps:

- welcoming, ID verification, questions to check the criteria of inclusion
- presentation of an information note, description of the objective of the study, the volume of blood collected, the risks associated with the sampling, the communication of the results, the rights of the participants, the confidentiality and the protection of the data.
- medical examination, answers to questionnaires and collection of the informed consent signed by the participants and by the physician who performed the examination.
- blood collection under fasting conditions in the morning
- snacks were offered
- interviews

To avoid a long waiting time, six investigators, a physician and several nurses were needed. Each participant file was prepared beforehand to save time. Participants often had to take a half a day off, and were invited to come under fasting conditions in the morning, sometimes until late in the morning. Moreover, the organisation allowed a contact with the people, who sometimes took the opportunity to ask questions and to discuss the topic of the incinerators.

### **Communication of results**

The main difficulty was linked to the communication of the serum levels of PCDD/Fs and PCBs, since no reference value is available. So, it is not possible to provide an interpretation of the health consequences of the individual results. However, the availability of serum levels for population non-exposed to the emissions of waste incinerators provided comparison levels, after adjustment on the confounding factors.

Lead in blood and cadmium in urine were also measured during this study, and the participants received these results with a health interpretation. When the levels were above the reference value, a phone discussion with a toxicologist was organised.

### Individual communication

Participants were asked whether they wanted to receive or not their serum levels (PCDD/Fs, DL-PCBs and PCDD/Fs + DL-PCBs). The majority wanted these results, which were transmitted with a letter and a summary of the findings of the study. Some participants expressed the desire to also communicate the results to their attending physician. The summary in the brochure which accompanied the letter of individual results presented:

- the geometric mean, minimum and maximum of serum dioxin levels (and congeners) observed in the study and comparison with foreign studies,
- the factors of variation (not linked with the exposure to the emission of waste incinerators),
- the geometric mean and the confidence interval of the levels, taking into account the factors of variation. Results were presented for the population exposed and non-exposed, for the whole study and for each of the eight locations.
- the characteristics of the most impregnated participants (serum levels above 99<sup>th</sup> percentile of the results).

This allowed the participants to compare their serum levels to the median or mean level of the whole studied population and of the local population (exposed or non-exposed, from a specific geographical area). No recommendation was given to the participants with the highest levels. None called the National Institute for Health Surveillance to obtain additional advice, more especially as they knew that a public meeting would be organized. It seems that most participants understood that their serum levels did not indicate any health risk.

#### General communication

For seven locations among the eight included in the study, the communication was done through oral presentations during public meetings. The meetings took place in the evening during about 3 hours and were organized by InVS with the assistance of the local authorities. The participation rate depended on the location (50 to 350 people). The media and several stakeholders (elected representative, NGOs, state services, industrials), usually came. A large exchange was set up with the population. One inconvenient of this type of communication is that some people do not dare to ask questions to "experts" in front of a large assembly. On the other hand, the whole assembly benefits from the answers to questions asked by the other people.

The questions mainly concerned the interpretation of individual results, the ways to reduce exposure, the results of the study for specific locations. It must be emphasized that due to a lack of statistical power, a detailed analysis of data for each location was not possible.

For one of the location where other studies had been conducted around the waste incinerator (studies on cancer incidence, cancer mortality and a risk assessment), the communication was organised over a whole day, from 10 a.m. to 7 p.m. Posters presenting the findings of the different studies were exposed in a room, and the people in charge of each study were there to answer questions. The objective was to encourage people to ask questions and to obtain answers adapted to their personal concerns and to their understanding capacities.

A large preparatory work was necessary to write posters understandable by the general public (simplifying the vocabulary, the method, and still being exact). At first, the local authorities were reluctant to this type of communication, since it implies a direct contact between the population and the scientists without the authorities.

Between 150 and 200 people took part. Discussions were long, often more than 30mn. Some people came with their individual results to discuss them. The main question was "how is it possible not to find anything (no higher serum levels and no excess of cancer) while the incinerator polluted so much?" Some refused to trust the findings of the studies (members of NGOs and complainants). However, the objective was not to convince, and the majority of the visitors understood the key message: studies were done by independent scientists to answer their questions, and resources were invested.

Whatever the type of communication, the participants appreciated receiving in-depth information on dioxins and on incineration. They also identified some individual behaviour likely to increase their contamination.

# Conclusion

Communication with the population is a key point during biomonitoring studies. During the recruitment, it allows to sample a population representative of the targeted population. During the blood and data collection, it enables you to gather reliable information. During the communication of the results, people will not question the results if the communication is well processed.

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# References

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