

Case study

A PARTICIPATORY PROJECT IN ENVIRONMENTAL EPIDEMIOLOGY: LESSONS FROM THE MANFREDONIA CASE STUDY (ITALY 2015-2016)

Bruna De Marchi^{1,2}, Annibale Biggeri^{2,3}, Marco Cervino⁴, Cristina Mangia⁵, Giulia Malavasi², Emilio Antonio Luca Gianicolo^{6,7}, Maria Angela Vigotti⁸

¹ Centre for the Study of the Sciences and the Humanities (SVT), University of Bergen, Norway

² Epidemiologia e Prevenzione "Giulio A. Maccacaro" Social Enterprise, Italy

³ Department of Statistics, Computer Science, Applications (DiSIA) "G. Parenti", University of Florence, Italy

⁴ Institute of Atmospheric Sciences and Climate, National Research Council, Bologna, Italy

⁵ Institute of Atmospheric Sciences and Climate, National Research Council, Lecce, Italy

⁶ Institute of Clinical Physiology, National Research Council, Lecce, Italy

⁷ Institute of Medical Biometrics, Epidemiology and Informatics (IMBEI), University of Mainz, Germany

⁸ (formerly) Department of Biology University of Pisa, Italy and Institute of Clinical Physiology, National Research Council, Pisa, Italy

Corresponding author: Emilio Gianicolo (email: emilio.gianicolo@uni-mainz.de)

ABSTRACT

Introduction: This paper reports the experience of a participatory project in environmental epidemiology, formally initiated in 2015 and still underway, in Manfredonia, southern Italy. We provide some background information and justification for our choice of a participatory model of investigation, and summarize the antecedents to our involvement, from the siting of a petrochemical plant in the area in 1971

to a series of events which triggered public discontent, concern and unrest.

Methods: We proceed by providing a description and discussion of the various steps of our study, focusing mainly on the dynamics of public engagement.

Results: The initial disappointment and mistrust of concerned citizens have been reduced. The consequent dialogue led to

a shared research protocol. Each step of the research has been made public and accessible.

Conclusion: We conclude with some remarks on our experience and the lessons we are drawing from it, including the challenges for its possible replication. The participatory project contributed to promoting public engagement and restoring some trust in scientific research.

Keywords: EPIDEMIOLOGY, SOCIOLOGY, COMMUNITY PARTICIPATION, EPIDEMIOLOGIC RESEARCH DESIGN

INTRODUCTION

Over the last few decades, public participation has been increasingly invoked and praised in thousands of European Union (EU) documents, declarations, programs and plans. In addition, its inclusion is mandatory in areas such as environmental planning and industrial risk assessment. Recently, the idea is penetrating fields, namely science and technological development, which were previously considered the

domain of experts alone. The Rome Declaration (1), while appealing to the principles on which the EU is founded, advocates the collaboration and reciprocal responsibility of virtually any potential stakeholder in, among others, the definition of research agendas and the conduct of research, and the access and application of its results.

The reasons behind this progressive appeal to participation and engagement are many and cannot be explored in this paper. Suffice it to say here that the

impulses for more inclusiveness are both top-down and bottom-up. As different as analyses and proposed solutions may be, the recognition is shared, in many quarters, that there is a crisis in the relationship between science and society and that this needs to be urgently addressed. This is particularly evident when risk and environment are involved, whereby “facts are uncertain, values in dispute, stakes high, and decision urgent” (2).

It remains to be seen whether the above trend is actually translated into meaningful action or is simply a rhetorical framing to continue with business as usual. As early as 1969, Sherry Arnstein published an article that became very influential in many areas of research. She writes: “There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process.” (3). She further warns against the risks of participation becoming just an empty label to cover different forms of manipulation. Similarly, some two and a half decades later, Fischhoff discussed the different ways of conceiving and treating the so-called public in risk communication activities, from exclusion to partnership (4).

Reports of experiences all over the world are by now countless, including very critical ones, such as the collection of essays by Cooke and Kothari, dealing mainly with development plans promoted by national and international organizations in post-colonial countries (5).

In research on health matters, there are many experiences in which patients, or their relatives and care providers (6), explore new pathways of medical research rooted in current information and communication technologies (7). A groundbreaking experience reported by Epstein (8) is the unconventional alliance between medical experts and so-called AIDS treatment activists in the USA in the 1990s. Together they redefined the design, data collection and interpretation of the clinical trials used to test the safety and efficacy of AIDS drugs.

To our knowledge, participatory studies are rare in the field of environmental epidemiology, at least if they are conceived – as we do in this article – to mean the full inclusion of so-called lay people in all of the research steps including: framing the issues under study; defining the objectives; designing the protocol;

selecting the methods of investigation; analysing; and reporting on results (9, 10).

Our aim in this paper is to describe a participatory approach to an epidemiological investigation. We adopted such an approach when we were requested to conduct an epidemiological investigation in Manfredonia – listed by the Italian Ministry of Environment as an area with high environmental risk (11). The reason for this choice was that Manfredonia, together with Flixborough, UK, and Seveso, Italy, was one of the cases that prompted the creation of the European regulation on major accident hazards. Epidemiological evidence of the consequences of toxic releases is still incomplete and residents continue to feel deceived and betrayed.

CONTEXT

Manfredonia is a coastal municipality of 57 331 residents in the Province of Foggia, Apulia Region, in southern Italy. Its traditional economy was based on fishing and agriculture until the late 1960s, when the Italian Government decided to site the Enichem petrochemical plant just outside the municipality's borders. The Enichem plant commenced operations in 1971, producing fertilizers and caprolactam, and employed some 1500 people, with 600 others working for sub-contracting firms.

On 26 September 1976, a scrubbing tower for the synthesis of ammonia exploded, releasing at least 12 tons of arsenic compounds into the atmosphere (12). The content of the release was revealed only in the days following the explosion, and the seriousness of the accident was downplayed. Over the next few years, several other accidents occurred, and some seriously alarmed the local population, such as the ammonia leak in 1978 which caused a mass evacuation from the city, or the fire in a caprolactam warehouse in 1984 (13).

Protests by citizens and environmentalists began in the 1980s and peaked in 1988 when the entire city rebelled against the decision of the Italian Government to divert the Deep Sea Carrier, a ship with toxic cargo originally and illegally destined for Nigeria, to Manfredonia (13). In the same year, the local Bianca Lancia Women Association applied to the European Court of Human Rights in Strasbourg complaining

about the Italian Government's inaction to assure the right to be informed about the risks derived by the factory accident. The judgment, pronounced ten years later, recognized the violation of Article 8 of the Convention on Human Rights by stating that: "... applicants had waited [...] for essential information that would have enabled them to assess risks they and their families might run if they continued to live at Manfredonia, a town particularly exposed to danger in event of an accident at factory." (14)

Mobilization and civic struggles continued for two years. The factory terminated the production of caprolactam in 1988 and ceased all operations in 1994. In addition, awareness regarding occupational risks was raised when a so-called barefoot epidemiological study – that is based on observations and data collected on the ground, not following pre-defined protocols – claimed a cluster of lung cancer cases. Evidence had been collected between 1995 and 1997 by Nicola Lovecchio, a former worker at Enichem diagnosed with lung cancer at the age of 45, and oncologist Maurizio Portaluri (15). The Court of Foggia initiated a case in 2002 against ten former managers of Enichem and two medical consultants which ended in 2007 with a non-guilty verdict. The judge ruled that a causal link between the occupational exposures and the claimed diseases had not been proved. The verdict was confirmed in appeals in 2011.

It is worth noticing that unsatisfactory results were not restricted to studies on exposed workers. Additionally, the epidemiological studies of the resident population produced equivocal and uncertain evidence (16): most of the uncertainty depended on the shortness of the observing period after the accident of 1976 compared with the latency of the onset of the oncological health effects. Including the Manfredonia area among those at high environmental risk (as noted above), and claiming an absence of evidence without properly appraising the related uncertainty, contributed to creating feelings of outrage and distrust among the local population.

APPROACH

In October 2013, the Mayor of Manfredonia, Angelo Riccardi – following up on advice from the oncologist, Maurizio Portaluri – contacted Maria Angela Vigotti, an epidemiologist, to request that a study be conducted on the health of the resident population, in order to

respond to local concerns linked to past Enichem activities. Ms Vigotti recommended the involvement of other researchers from different backgrounds, including medical statistics, environmental physics, sociology, and history. She also insisted on a vast communication plan for targeting a variety of stakeholders who would have a say in all phases of the study. Her suggestions were accepted and a contract was signed in January 2015 between the National Research Council (CNR), the Manfredonia Municipality and the Local Health Unit (LHU).

The study aimed to assess the health status of the local population and the potential effects of pollution from the petrochemical plant in the period 1971–1994, with special regard to the 1976 accident. Table 1 reports the main phases of the study, with outcomes and comments.

Phases 1 and 2 (see Table 1) document the preliminary agreements on the composition of a mixed Research Group (RG) and the overall participatory approach of the study.

Phase 3 was especially crucial, as it included a public statement by us, the authors of this paper, and members of the Research Group, about our role in the study. We claimed that we did not position ourselves as external, value-free observers, with no stakes in the issue. Rather, we conceived of ourselves as belonging to an epistemic community – “a network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area” (17). Coming from different disciplines and backgrounds, we share a set of normative and principled beliefs, including that research must contribute to human welfare and social justice. In this perspective, we maintain that the quality assurance of our scientific inputs to the policy process requires the participation of an "extended peer community", consisting of all those with a stake in the issues under scrutiny (2).

In other words, if the policy purpose is to safeguard the health and well-being of the citizens of Manfredonia, we believe and demand that those very citizens have a say on how to devise the most appropriate and effective problem-solving strategies for amending past blunders and wrongs and preventing their repetition. While reopening a 40-year-old case, we were and are looking at the future: and neither the past nor the

future can be constructed without the testimony and the contribution of those affected.

The subsequent phases followed without us devising any specific methods or techniques to involve the population. We simply opened up the process by getting involved in as many events as possible, where we openly stated the convictions illustrated above and presented the activities planned under the study contract, inviting public discussions.

The study phases were documented in the official journal of the Italian Epidemiological Association (www.epiprev.it) and reported in a dedicated website (www.ambientesalutemanfredonia.it). The latter also contains all other documents of relevance, including financial ones.

DISCUSSION

At first, the idea of this new research met with widespread skepticism among the population, or rather the concerned citizens – those interested in the protection of health and the environment. Due to previous disappointments, the local trust in institutions – administrative, political, scientific, and legal – had been considerably reduced. However, after a series of encounters, the new initiative sponsored by the municipality gained credit thanks to – we maintain – both our public declarations of non-neutrality and the informal endorsement of some respected local witnesses, most notably the already cited oncologist, Maurizio Portaluri.

Among the citizens that showed interest and support for the initiative were many who had been involved in the previously mentioned protests and mobilization against the Deep Sea Carrier and the Enichem petrochemical plant, and who had never discontinued their commitment in defense of health and the environment.

A Citizen Committee (CC) called *Coordinamento* was created, open to all and without any formal structure. Its double purpose was to maintain a continuous dialogue with the Research Group and local authorities on the one hand, and involve as many residents as possible in research and policy activities on the other.

After the inception, there was a constant dialogue – both face-to-face and at a distance – between the Research Group and Citizen Committee via e-mail, telephone conferences and other means. Meetings in person were organized whenever the researchers travelled to Manfredonia, either in public events – usually with local authorities – or in open meetings held in the headquarters of the Citizen Committee made available by the Local Health Unit.

The format of the Citizen Committee had both advantages and disadvantages. On the one hand, any interested person could join at any time, bringing new information and ideas and, most importantly, helping to expand the network of interested individuals, groups and associations via personal and professional contacts. Of course, not all attempts of inclusion were successful and some individuals and groups refused to participate in the workings of the Citizen Committee, or left after an initial involvement, at different times and for various reasons.

On the other hand, the lack of structure created some representation problems, as the more active associates developed a closer relationship with the Research Group – or some of its members – through more frequent contacts, including informal ones. This was at times interpreted by others as a privileged relation or even a lack of transparency. In general, conflicts and confrontations were far from rare within the *Coordinamento*, as is inevitable – and possibly vital – in any group. Dissimilar political preferences and alliances reverberated inside the Citizen Committee, such as for the assessment of local politics. There were contrasting views about preferred organizational and strategic choices. Commitment and continuity were unequal – or at least were perceived as such – among participants, and this generated some resentment which was at times openly declared, but more often it was creeping and underground. Last but not least, personality clashes occasionally endangered the possibility of coordinated action.

It is not our purpose here to analyze such dynamics in detail; nor is it possible, as we do not have sufficient direct knowledge of them. We perceived them through formal or informal reports, and only occasionally did we observe them directly. In any event, and despite the unequal and discontinuous engagement and commitment of its affiliates, the *Coordinamento* was able to achieve some important

successes, both in orienting the research process and in promoting related activities. Among the latter were a series of initiatives organized in September 2016 to commemorate the accident of 40 years before and its local impact and consequences. Overall, support for the research endeavor and the Research Group itself never failed. More recently, the Citizen Committee selected two spokespersons – a man and a woman – with the main task of easing communication with the Research Group – although this by no means implies that they are the only ones entitled to speak on behalf of the Citizen Committee.

CONCLUSION

Manfredonia is one of countless examples of a community being exposed to chemical hazards and pollution without adequate awareness and preparedness, and possibly even without an adequate risk assessment (18). It is one of countless instances of a population suffering from the consequences of an accident affecting its health and well-being, including all kinds of material, psychological and social aspects (19). Moreover, it is one of countless cases in which the burden of proof is left with those who have experienced the damage, and where evidence of tort is deemed insufficient in court, thus adding to the wrongs already suffered (20).

And yet, each case is unique, and so is that of Manfredonia. Here, we do not have the space to analyse its peculiarities. Suffice is to say that a key aspect which favored the possibility of implementing a participatory research model was the presence of a number of citizens who, through the decades, never gave up their attempts to be recognized as active subjects in the decision processes regarding the future of their community. They were our primary reference group and our source of encouragement and support. As already mentioned, the local reservoir of trust was almost exhausted when the Research Group was formed, due to multiple previous disappointments. Thus, as a group of researchers, we had to gain people's confidence in the field. We did so by openly stating our position about the non-neutrality of (our) research, and sticking to our conviction that the local population – which had been exposed to accidents and environmental pollution – was fully entitled to speak and act in defense of its past, present and future

interests. As noted earlier, the endorsement by some respected local witnesses was also very important.

As so very often happens with health and environmental conflicts, at the beginning, the population did not seem to be intrigued with the technicalities of the exposure studies. Most residents were already convinced that they had been poisoned by the plant through accidents, normal operations and waste dumping. They were mainly asking for justice and a scientific confirmation of what they already knew.

It should be clear from our presentation that there is no way to account for or measure a participatory experience like this in terms of numbers. Thus, in agreement with Saltelli, we “insist on a ‘license not to quantify’ when the conditions for responsible quantification are not met” (21).

We have been frequently asked – and ask ourselves – whether our practice can serve as a model. Our answer is: Yes, with caution. Also in light of recent epidemiological literature (22), we feel entitled to recommend the adoption of participatory approaches in epidemiological studies. Public engagement can be encouraged via many different methods and techniques according to local circumstances and needs. As we consider our approach seminal – at least in epidemiology – we purposely refrain from providing any detailed assessment or recommendation. Any new experience requires a critical investigation of the situation at hand in order to select the most appropriate course of action. Yet, the overall purpose should remain that of promoting an alliance between local communities and experts in designing and implementing policies addressed to protect public health, safety and well-being.

As we stated earlier, in setting up a participatory process, it is important that the researchers feel part of an epistemic community (17) sharing a set of common normative values across professional disciplines and competencies. Such values include reciprocal respect, humility, and the commitment to accept being part of an extended peer community (2) where available scientific knowledge is evaluated also by non-scientists and considered together with other types of knowledge derived from familiarity with the territory, acquaintance with local lifestyles, personal and professional experiences, and local traditions. Such a commitment is sometimes burdensome and consequently needs to

TABLE 1. PHASES OF THE MANFREDONIA PARTICIPATORY EPIDEMIOLOGICAL STUDY

Phase n° and date	Promoter	Subjects involved	Outcome	Comment *
1. October 2013	Mayor	Principle investigator (PI) Epidemiologist	Preliminary agreement between the Municipality, the National Research Council (CNR) and the Local Health Unit (LHU)	Study conceived as participatory
2. December 2014	PI Epidemiologist	PI with other researchers	Definition of the interdisciplinary Research Group (RG)	Inclusion of other disciplines such as environmental, physics, sociology and history
3. February 2015	Mayor and RG	Population	Presentation of the project and its conceptual premises to stakeholders and residents	Critical appraisal of previous studies, uncertainty evaluation, and declaration of "non-neutrality" of the research
4. May–June 2015	Population and RG		Definition of the epidemiological questions	Open debate on the study design as outlined in the agreement
5. September 2015	Mayor, Population, and RG		Design of various scenarios with respective health policy implications	Anticipation of possible study results and their policy implications
6. December 2015	Population and RG		External peer review of the study protocol	Reviewers selected by all stakeholders
7. February–June 2016	Population and RG		Implementation of the study and preliminary results	RG members discuss with the population all aspects of the ongoing study, including technical ones
8. September–December 2016	Population and RG		Public discussion of results and related uncertainties	Critical appraisal of the difficulties encountered and the limitations of the study
9. Ongoing	Mayor, Population, and RG		Implications and future challenges	To be discussed in multiple forums

* In the "Comment" column we highlight some key activities in the involvement of the population.

be constantly checked, renewed and confirmed. This is what we did and are doing, throughout the process, both individually and collectively.

We encouraged, and genuinely considered, local inputs, comments and criticisms to the study design, its conduct and analysis of results. This kind of two-way communication about risks proved effective both in disseminating accurate information and in dispelling feelings of suspicion and outrage.

Finally, and importantly, it contributed to promoting public engagement and restoring some trust in scientific research.

Acknowledgements: The authors wish to acknowledge the contributions of Antonella Bruni and the Manfredonia Citizen Committee (*Coordinamento*). This original article is also part of the PhD of Emilio A. L. Gianicolo at the University of Mainz, Institute for Medical Biostatistics, Epidemiology and Informatics.

Sources of funding: This project was founded by the Municipality of Manfredonia and co-founded by the

Italian National Research Council. Annibale Biggeri was partially sponsored by the Italian Ministry of University and Scientific Research.

Conflicts of interest: None declared.

Disclaimer: The authors alone are responsible for the views expressed in this publication and they do not necessarily represent the decisions or policies of the World Health Organization.

REFERENCES

- Rome Declaration on Responsible Research and Innovation in Europe. *Science, Innovation and Society: achieving Responsible Research and Innovation*; 2014; (https://ec.europa.eu/research/swafs/pdf/rome_declaration_RRI_final_21_November.pdf, accessed 15 May 2017).
- Funtowicz S, Ravetz JR. Science for the post-normal age. *Futures*. 1993;31(7):735-55.
- Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of Planners*. 1969;35(4):216-24. 10.1080/01944366908977225.
- Fischhoff B. Risk perception and communication unplugged: Twenty years of process. *Risk Analysis*. 1995;15(2):137-45. 10.1111/j.1539-6924.1995.tb00308.x.
- Cooke B, Kothari U, editors. *Participation: The new tyranny?* New York: Zed Books; 2002.
- Riggare S. Patient activist. Nuffield trust: Evidence for better health care. 2016. (<http://www.nuffieldtrust.org.uk/about/our-people/sara-riggare>, accessed 19 December 2016).
- Wicks P. Subjects no more: what happens when trial participants realize they hold the power? *BMJ*. 2016. (<http://www.bmj.com/content/348/bmj.g368>, accessed 19 December 2016).
- Epstein S. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Sci Technol Human Values*. 1995;20(4):408-37.
- Simpson BW, Truant P, Resnick BA. Stop and listen to the people: an enhanced approach to cancer cluster investigations. *Am J Public Health*. 2014;104(7):1204-8. 10.2105/AJPH.2013.301836.
- Lichtveld M, Goldstein B, Grattan L, Mundorf C. Then and now: lessons learnt from community-academic partnerships in environmental health research. *Environ Health*. 2016;15(1):117. 10.1186/s12940-016-0201-5.
- Parlamento Italiano, Nuovi interventi in campo ambientale 426. *Gazzetta ufficiale numero 291 del 14 dicembre 1998*. 1998 [in Italian].
- Liberti L, Polemio M. Arsenic accidental soil contamination near Manfredonia. A case history. *Journal of Environmental Science and Health Part A: Environmental Science and Engineering*. 1981;16(3):297-314. 10.1080/10934528109374983.
- Malavasi G. Manfredonia. Catastrofe continuata, cittadinanza ritrovata e colpevole rimozione. *Epidemiol Prev*. 2016;40(6):389-94 [in Italian].
- European Court of Human Rights, Guerra and Others versus Italy. Case number 116/1996/735/932 Council of Europe. 1998.
- Langiu A, Portaluri M, editors. *Di fabbrica si muore*. San Cesario (Lecce): Manni Editore; 2008 [in Italian].
- Mitis F, Martuzzi M, Biggeri A, Bertollini R, Terracini B. Industrial activities in sites at high environmental risk and their impact on the health of the population. *Int J Occup Environ Health*. 2005;11(1):88-95.
- Haas PM. Introduction: Epistemic Communities and International Policy Coordination. *International Organization*. 1992;46(1):1-35.
- Fjelland R. When laypeople are right and experts are wrong: Lessons from love canal. *International Journal for Philosophy of Chemistry*. 2016;22:105-25.
- Consonni D, Pesatori AC, Zocchetti C, Sindaco R, D'Oro LC, Rubagotti M, et al. Mortality in a population exposed to dioxin after the Seveso, Italy, accident in 1976: 25 years of follow-up. *Am J Epidemiol*. 2008;167(7):847-58. 10.1093/aje/kwm371.
- Cranor CF, editor. *Toxic tort: Science, law, and the possibility of justice*. Cambridge: Cambridge University Press; 2006.
- Saltelli A. Young statistician, you shall live in adventurous times. *Royal Statistical Society*. 2016;12(6):38-41. 10.1111/j.1740-9713.2016.00983.x.
- Buyx A, Del Savio L, Prainsack B, Volzke H. Every participant is a PI. Citizen science and participatory governance in population studies. *Int J Epidemiol*. 2017. 10.1093/ije/dyw204.