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# Conclusion: Is It Really Possible to Take the Floor (Agnostically) About Refused Knowledge?

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### 11.1 Conclusion: Is It Really Possible to Speak (Agnostically) About Refused Knowledge?

Nowadays, the governance of issues with in-depth technoscience involvement has moved to the forefront of both the political agenda and the public debate. Against this backdrop, it would seem that all scholars (be they rooted in social science, humanities or the natural or physical sciences) agree on the need to carefully open up the science-society nexus for inspection, with all its ambivalences and conflicts. Whatever their varying research purposes and needs in analysing this nexus, what identifies a critical point of attention is the heuristics potential of the various analytical stances scholars may adopt, from time to time, in order to discern the social conditions under which different groups of people

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confer credibility and trust on specific knowledge claims and knowledge-making practices, whether they are grounded within the boundaries of science or otherwise. This implies properly examining the interplay between science—and the institutional arrangements supporting it—and those who engage in efforts to elaborate knowledge claims which are alternative or opposed to science and its plausibility in orienting decision-making processes around issues affecting collective life. This requires a research framework that—as we outlined in the introductory chapter of this volume—carefully takes into account the positionality of scholars observing concerned instances of science contestation, and how the pertinence and scientific adequacy of the research questions are defined.

As we have tried to highlight throughout this book, research into challenges to science and techno-scientific expertise is not necessarily novel for scholars, especially those concerned with science and technology studies (STS). What is—at least partially—new is the intellectual trajectory adopted here, a trajectory that has taken the 'Going Out' call issued in a famous essay by the same name by Harvey Molotch (1994) seriously. This call urges us, as scholars, to venture beyond the comfort zone of our knowing niche, since without a deep and immersive relationship with the phenomena we study we are incapable of mobilising suitable analytical lenses to avoid simplistic representations and interpretive blind spots.

From a methodological point of view, responding positively to Molotch's call is undoubtedly a challenging task requiring us to reflexively reconsider our positionality as professionals embedded within a prevailing epistemic institution, i.e. academia. In fact, it entails interacting with social worlds that consider our academic profession and institutions as part of the problem they need to address and—whether we like it or not—to solve sometimes in a conflicting rather than negotiating way. Indeed, one of the most interesting awarenesses which progressively emerged during the fieldwork on which this volume is based is that we cannot understand RKCs without also learning something about ourselves. And when we say 'ourselves', the reference is at least twofold.

Firstly, by 'ourselves' we mean subjects who do not self-identify as follower of RKCs. Hence, while contributing to the framing of RKCs as actors holding knowledge rejected by science, we position ourselves reciprocally on the side of the prevailing epistemic regimes. Secondly, and more specifically, by 'ourselves' we also mean 'subjects-sociologists-STS scholars' identifying refused knowledge as suitable research objects with which to disentangle the multifaceted interplay between knowledge-making practices, expertise and society. We thus need to ask ourselves what we have learned about RKCs and ourselves.

#### 11.1.1 Refused Knowledge Communities and Us

This book has highlighted that RKCs are not a homogeneous entity but rather a kind of *seamless web*: an articulated and differentiated universe with individual instances and cultural values, ethics and politics which sometimes conflict with one another. Hence, they are peculiarly characterised by a multifaceted internal articulation of human and non-human agents, plural positions on science, public institutions, health-related policies and, in general, regarding the social and natural world which we, as humans, are engaged in.

It might rightly be objected that this is not a ground-breaking insight. However, it is only by attempting to consider all the specific RKC perspectives that we can move beyond the standardised and simplistic interpretative lens we are confined to when the going out approach is not followed. This latter is an approach which allows us to avoid hastily dismissing RKCs as irrelevant minorities made up of ignorant, irrational individuals who have naively fallen into the fake news trap, or artfully seek to discredit science and its institutions. In other words, an approach which avoids referring to common sense as an explanatory factor. Furthermore, the going out approach is insufficient without an agnostic stance, which requires a radically symmetrical perspective to observe an empirical phenomenon that is rich in nuances, corresponding to ambivalent and plural stances on science and its institutions and representatives. These ambivalences can be animated by diverse and, to a certain extent, legitimate doubts and questions. Sometimes, these doubts and questions are so legitimate that they might easily be shared by all of us. Surely it is legitimate to assert that science governance and defining the scientific agenda should be transparent and that relevant stakeholder engagement is desirable? Surely it is legitimate to demand that the voice of citizens

and concerned groups of people should be listened to more than they currently are when decisions of collective relevance need to be made, especially when the scientific community is itself not in full agreement on them? Is it not true that even in government institutions, it is now generally accepted that citizens are not mere consumers of scientific knowledge and technological outcomes, but active actors with a right to take an active part in public scrutiny and co-definition of techno-scientific issues? Accusing those who engage in a contentious relationship with science of demagogy, irrationality or scientific illiteracy is no more than a shortcut to not taking seriously the fact that the interface between science and society is increasingly bound up with the quality of democratic processes.

The realm of refused knowledge is also far from static: RKCs operate within a constantly changing dynamic which shifts together with its historical, political and socio-technical contingencies. Such contingencies potentially rearrange relations between RKCs themselves, as well as with other social worlds (i.e. the scientific institutions and their representatives). In this regard, the COVID-19 pandemic situation is a significant post-normal science landscape Funtowicz and Ravetz 1993, both showcasing RKC dynamism and highlighting processes that would have otherwise been more difficult to understand. Indeed, the polarisation mechanism at work during the pandemic, especially within the media ecosystem at large, highlighted the role played by the normative labelling of RKCs (as irrational enemies) within the subjectivation and countersubjectivation processes applied to both the followers of refused knowledge and those with whom they interact 'from the outside' (i.e. once again the scientific institutions and their representatives). The rejection by scientific institutions of the knowledge elaborated at the fringes of, or outside the confines of, science is, in fact, the basis for RKCs' processes of self-recognition and belonging. At the same time, the rejection of other, competing, sources of knowledge contributed, in a complementary way, to reducing the uncertainty surrounding the Covid-19 pandemic. Identifying a sort of dangerous and morally reprehensible enemy (i.e. subsuming all potential critiques to science under the one-size-fits-all label of 'irrational critique') strengthened the authority of a scientific knowledge which faltered during the pandemic under the weight of the urgent demands arising from the need to deal with a situation that was, in many respects, unprecedented and replete with uncertainty.

Our professional and disciplinary stances were also at stake in this interplay. The constant exercise of reflexivity that accompanied our research work made us increasingly aware that the sociological vision, like other disciplinary analytical visions, is bounded within a hic et nunc (here and now) standpoint that inevitably prevents it from remaining impartial. It might be said that this awareness took shape through two phases, although this does not fully capture the complexity and difficulties that arise in empirically studying refused knowledge. We initially viewed the relevance of the symmetry principle as a methodological compass. Without distancing ourselves from mainstream assumptions prejudicially dismissing RKCs as a phenomenon rooted in a lack of scientific literacy or an irrational mindset, we would not have been able to fully comprehend the processes that lead people to legitimise and endorse knowledge rejected by the scientific and public institutions. But this was relatively straightforward. What required slower and more challenging maturation was the realisation that we, too, were contributing to the co-definition of RKCs simply by choosing them as the object of our empirical enquiry. This realisation involved recognising our role, as researchers, in shaping the narrative and interpretative frameworks of these refused bodies of knowledge. It required acknowledging the power dynamics at play and critically reflecting on the potential implications of our research and its possible impact on the way RKCs are perceived and understood. This process of self-reflection regarding our own position within the field under scrutiny was a crucial and ongoing aspect of our research journey.

This may seem superficially simple or even banal, but epistemologically it is more radical and its implications may be more profound than those of the decision to adopt a symmetrical approach. The most significant consequence is that even a polished and symmetrically oriented sociological perspective cannot claim to be entirely 'innocent' or impartial—that is, it is not immune to the processes of demarcation that classify actors into hegemonic and subaltern groups, according to certain ethical and moral values. It may involve a juxtaposition with strong performative implications. Understanding the mutually constitutive relationships between RKCs and their 'polemical others', namely scientific

communities, requires considering researchers engaged in fieldwork as actors taking part in the definition of the phenomenon itself. Studying RKCs is not simply a matter of their denotative representation but rather opens up the analytical task to an only partially manageable process that contributes to the public construction of refused knowledge as both research object and social concern. The relationship between researchers exploring refused knowledge and RKCs themselves is therefore performative, in the sense that representations of RKCs are inevitably drawn into the co-definition of their context of action and societal relevance.

Another aspect related to our research work concerns the motivations and drivers underlying the process by which credibility and trust are conferred on refused knowledge. Once again, our understanding may seem banal. But this point is important in shining the spotlight on the fact that a body of knowledge refused by science can be recognised as reliable by people not only because it is capable of addressing issues neglected by institutional actors but also for its ability to support everyday life meaning-making processes affecting biographical trajectories. This is particularly true where illness-related refused knowledge is concerned, as this inevitably brings up painful and deeply troubling contingencies.

The relationship between a biographical contingency (e.g. a condition of malaise or illness) experienced as highly problematic and difficult to solve, and the search for knowledge and answers outside what is generally accepted in our socio-cultural context should not be underestimated for at least two reasons. Firstly, because the attempt to make sense of uncertainty and concerns such as health and illness issues by resorting to refused knowledge has a great deal to tell us about some of today's most significant socio-cultural trends. If, in fact, some segments of our societies turn to alternative interpretational resources for answers to emerging issues and concerns, it means that such answers are not (readily) available within institutionally recognised expertise. This may mean both that we live in a world in which scientific knowledge and tools are sometimes incapable of supporting people in situations of difficulty or suffering, and that some of the interpretational resources elaborated by science—and which have proved to be valid in the past—have not been effectively replaced with alternatives. Secondly, the search for refused knowledge highlights the relevance of highly existential questions, however

questionable or even dangerous the way RKCs attempt to address these may be, given the potential consequences of mobilising refused knowledge on health and well-being. Indeed, as we have argued, the motives behind the endorsement of refused knowledge can highlight the need for resources capable of making sense of controversial situations or reducing the potential uncertainty for everyone, not just RKC members. And it is no accident that when the level of uncertainty increases due to particularly destabilising events such as a pandemic, the degree of attention to alternative forms of knowledge also grows.

Our arguments thus far also increase our understanding of the similarity we have observed between the legitimisation strategies mobilised by both scientific knowledge and refused knowledge. However, this similarity leaves the question as to where the demarcation line between scientific knowledge and refused knowledge is to be located unanswered: Is it merely a matter of epistemic positioning and labelling? Is it solely a matter of a different distribution of power, that is, the authority and moral force to define a situation, and then establish how to understand it by mobilising a specific worldview? The answer to these questions is apparently 'no'.

But if we answer the above questions negatively, are we obliged to accept a reductionist explanation such as 'science is true, while refused knowledge is false'? We believe we have demonstrated that analytical alternatives are possible, however less easy to deal with these may be. Indeed it is, at the very least, not the sociologist's task to suggest what is true or false from a scientific standpoint but rather to shed light on the social processes by which bodies of knowledge are accorded legitimisation and credibility, whether for the scientific community or for a community of lay people discussing the basis for the decisions such as whether to vaccinate their children.

## 11.2 "Taking a Stance Without Taking a Side": Testing the Harambam Methodological Stance

At this point, however, we may posit another problem, already well outlined by Jaron Harambam (2020), as we saw in the introduction to this book: is it 'taking a stance without taking a side' (p. 235) possible?

In translating Harambam's instance to our specific field of inquiry, we may ask to what extent it is legitimate to speak about refused knowledge in a sociologically relevant manner without necessarily dismissing it as (dangerous) informational junk. The tone and content of the public debate during the COVID-19 pandemic certainly exacerbated the rift between the knowledge accepted by scientific communities and institutions, and the knowledge they refuse. It thus shaped a strong, and to certain extent naive, polarisation between science and anti-science that still makes it difficult to speak symmetrically about refused knowledge without running the risk of being classified as supporters of it. However, the rift between scientific and refused knowledge per se is not new; the public debate during the COVID-19 pandemic simply amplified it and made it more publicly visible. Such a rift existed even before the pandemic, although it may have been more latent and less radical in form. Hence, what is it which makes it difficult to 'take a stance' from which to analyse refused knowledge symmetrically, exploring the point of view of its supporters, 'without taking a side'? In our view, the challenge involved in resolving this (possibly only superficial) contradiction depends to a large extent on the permanence of a series of ready-made normative prejudices and interpretative blind spots regarding the current challenge to science as well as about refused knowledge.

On the basis of our research work, we can identify some of these more persistent interpretative blind spots. Here, we will consider the exemplary case of those known in Italy as *anti-vaxxers* (in this book called *pro-vaccine choice*). In this regard, it is worth noting that the idea by which those casting doubt on vaccines are necessarily hostile to science at large is not empirically founded. Quite the opposite: it is scientific experts or exponents of science which summarily dismiss the public quest for

transparent information about immunisation policies as irrational and stemming from ignorance. By contrast our observations show that scepticism of immunisation policies rarely associates with a rejection of science per se. Similarly, vaccine refusal is often not definitive or irrevocable. The term *vaccine hesitancy* was coined precisely to indicate an attitude of concern regarding the safety and efficacy of vaccines. Those simply postponing vaccination are similarly hesitant, as is often the case of routine paediatric vaccination, or those deciding to accept only certain types of vaccines. It is, therefore, a nuanced attitude that often indicates a higher level of awareness about science and the need for understanding and discussion around public health policies.

However, there is still a preference for considering RKCs in a reductive and thus misleading way, for example, by mobilising the idea that those who question certain pieces of scientific knowledge must necessarily be contrary to science as a whole. For RKCs, the opposite is not infrequently true, as we often find a high degree of trust in science in general amongst them. Doubts about certain specific scientific issues, particularly those related to health and well-being, often arise because of direct or indirect personal experiences, such as a pharmacological treatment that has caused severe side effects, or a diagnosis of a rare disease for which there is still no effective treatment, leaving patients feeling lonely and powerless. It is also not uncommon for patients and their families to perceive a lack of attention to their identity as individuals, their emotional spheres and the socioeconomic constraints that may limit access to health services and therapies from the biomedical milieu. This perception can fuel the belief that medical and healthcare professionals (as well as their knowledge and technologies) contribute to an increasing dehumanisation of patients and the caregiving relationship. However, all of this does not necessarily imply a rejection of science in general. It is not surprising, indeed, that the same RKCs often advocate for a 'purer' science, that is a science free from political interference and economic interests. This is undoubtedly an idealistic, naive view of science but it demands for greater transparency in the scientific knowledge validation processes, especially when such knowledge becomes the reference basis for public health policies.

A second blind spot deserving of our attention relates to what public communication of science and technology scholars have called the *deficit* 

model Trench (2008). The idea underlying this model is as simple as it is misleading: people adopt sceptical attitudes to science and engage in irrational behaviours because they lack adequate scientific literacy. Despite widespread criticisms of this approach for its abstract, simplistic and linear conception of the relationship between science, technology and society, it remains deeply ingrained in our cultural context, if only because it benefits from the simple explanation factor (poor scientific literacy) for a complex problem (criticism or a sceptical view of certain pieces of scientific knowledge) combination. It is not surprising, then, that we also find the deficit model being used to account for RKCs. According to this simplistic approach, those who belong to these social worlds hold scientifically unfounded knowledge due to their lack of education or limited scientific literacy. However, RKC members encompass many individuals with medium-to-high educational levels, including some doctors and researchers. Furthermore, if we consider the most extensive network of relationships in which RKCs are embedded we sometimes also find individuals with strong scientific credentials (see Chap. 7).

Another interpretative blind spot can be summarised as follows: anyone distrusting science is a conspiracy theorist. Although RKCs share a widespread scepticism of pharmaceutical or biotechnology companies, as well as institutional bodies such as national and supranational medical agencies, this does not mean that they systematically justify their critical claims with broad conspiracy theories. It is, in fact, common for RKCs to express strong reservations or harsh criticisms of the merits of conspiracy theories. Therefore, using this concept to stigmatise RKCs risks hindering understanding of their concerns. For example, those who claim to suffer from *electrosensitivity* argue—against the scientific consensus—that further scientific inquiry into the link between a set of physical and psychological symptoms and the exposure to electromagnetic fields is needed. Therefore, they do not rely on conspiracy theories to support their hypothesis but rather seek support from doctors and researchers in their efforts to reorient the scientific agenda on this topic.

The reductionist interpretation of RKCs as a field delimited by scientific illiteracy, ignorance and irrationality is also guided by a conception that it is only scientists who have the right to *be considered* experts, especially within the media ecosystem. Generally speaking, when we refer to

an expert, we imagine someone with specialist expertise in a specific and well-bounded scientific domain. However, as we saw during the COVID-19 pandemic, the experts called upon to speak in the media or involved in advisory committees supporting policymakers were diverse figures, such as virologists, infectious disease specialists, epidemiologists and data analysts. These were asked to come up with answers not only on the nature of the virus and its diffusion on which they had specialist knowledge, but also about matters such as school closures or restaurant access restrictions, i.e. issues with economic, social and ethical implications in which their opinions were not inherently more authoritative than those of other people. This way of exercising techno-scientific expertise in the public sphere assumes that scientists are to be considered *experts* on everything per se and conversely, that all that expert status is automatically accorded to scientists, whatever their specialisation.

However, the seminal work by Funtowicz and Ravetz (1993) on postnormal science and many other related contributions about the governance of science and technology (see Epstein, 1996; Jasanoff, 2007; Weingart, 2023) underlines that we should be aware that where decisions with potentially powerful implications for a variety of social groups and categories are concerned, different types of expertise can play a relevant role in supporting the alignment between techno-scientific development and society. It is not only techno-scientific expertise that matters, but also knowledge rooted in the everyday experience of groups of citizens, workers, families and non-governmental organisations directly involved in the contexts affected by these decisions. Ignoring people's experiential knowledge and expertise can lead to poor decision-making unaligned with the values, needs and requirements of the social contexts in which they are to be implemented.

Underestimating the knowledge of those who, as non-scientists, are not publicly recognised as *experts* is therefore a risk not only for science itself but also for its social implications. Hence, the recent COVID-19 pandemic provided an opportunity to analyse the consequences of an overly simplistic conception of what counts as expertise. The policies implemented in response to the emergency were largely justified on the basis of scientific evidence provided by dedicated advisory bodies made up of techno-scientific experts. Thus, for example, policies regarding the

vaccination campaign or the ensemble of prescribed norms (e.g. physical distancing measures or mandatory use of personal safety protection devices) to contain the spread of Sars-Cov-2 were justified as linear, neutral and self-evident emanations of scientific knowledge. This created the conditions by which those criticising public health policy could be stigmatised and excluded from legitimate public debate as inherently antiscientific, and thus irrational. However, such a rhetorical strategy is based on an idealised and technocratic representation of the relationship between scientific knowledge and public regulation. Scientific knowledge is, in fact, rarely directly actionable in the realm of policymaking. On the contrary, the process that leads from scientific knowledge to political decisions is always open to negotiation between the interests and political positions of a range of stakeholders. As a result, translating scientific knowledge—for example, knowledge about the nature of Sars-Cov-2, its transmission mechanisms and its effects on human beings—into public policies to achieve specific objectives such as limiting the diffusion of the virus should involve marshalling a wide range of expertise and knowledge to govern the economic, environmental, social and psychological implications of the policy choices adopted. In any event, such decisions can be contested without necessarily directly implying questioning the scientific knowledge itself.

The various interpretative blind spots briefly outlined thus far contribute to defining a situation that seems to leave no way out: an idealised view of our relationship with science, an uncritical reliance on the deficit model, a metonymic rhetorical strategy that homogenises RKCs into ignorant conspiracy theories, a reductionist conception of expertise and its relationship with politics and policymaking. The combined effect of these interpretative blind spots forces us into an epistemological trap that limits the heuristic relevance of the analytical stance.

It would thus seem that there may be no viable middle way between labelling RKCs derogatively or supporting them, but this is, perhaps, not the task of this book. We have, at the very least however, tried to outline a way out which—we realise—requires further collective effort if it is to be better defined and translated into precise research currents also capable of offering critical science, technology and innovation governance insights.

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