



Manufacturing Refused Knowledge in the Age of Epistemic Pluralism

Discourses, Imaginaries, and
Practices on the Border of Science

Edited by

Federico Neresini · Maria Carmela Agodi
Stefano Crabu · Simone Tosoni

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About This Book

The COVID-19 pandemic has clearly shown how knowledge refused by scientific institutions can be endorsed by diverse segments of our societies for addressing health, illness, and well-being. Despite this sharp evidence, the understanding of current cultural perspectives and discourses questioning the epistemic authority of science tends to be jeopardized by a normative view that reduces such refused knowledge to an irrational and deviant mindset to be opposed in order to preserve democracies and the well-being of our societies. Assuming an agnostic analytical stance over its epistemic value, this book aims to analyse the processes through which refused knowledge receives epistemic credibility, which people are engaged in such processes, how they relate with prevailing epistemic institutions and in which ways they practically enact a body of refused knowledge in their everyday lives. The book, drawing on an extensive three-year mixed-method empirical research, shows that it may be less helpful to frame the contestation of the authority of science in terms of an irrational “zeitgeist”, than to treat refused knowledge as a more peculiar mode of knowing the world and ways of addressing the uncertainties that inevitably affect our everyday life. Indeed, people involved in social worlds within which refused knowledge plays a pivotal role engage a complex dialectic with prevailing scientific institutions that are increasingly embedded in a societal landscape featured by an epistemic pluralism.

As a consequence, *taking refused knowledge seriously* helps not only to better understand the legitimation processes that confer credibility to knowledge claims otherwise refused, but also to analyse how knowledge is, at large, the result of sociotechnical assemblages. The book thus offers a relevant contribution for scholars and students from a range of disciplines interested in the understanding of the changing relations between science, expertise and society, including Science and Technology Studies, Sociology, Media Studies, Cultural Studies, and Anthropology. At the same time, it also speaks to a wider audience concerned with the public debate over the supposed crisis of scientific expertise in the post-truth era, as well as the current mistrust towards the political and scientific establishment and their knowledge.

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1

Introduction: Manufacturing Knowledge at the Border of Science

Stefano Crabu, Federico Neresini,
Maria Carmela Agodi, and Simone Tosoni

1.1 Introduction: Manufacturing Knowledge at the Border of Science

This book focuses on a timely and currently highly controversial topic with considerable resonance in academic circles, amongst policymakers and in the broader public sphere. The central research question it explores is: How and under which conditions do groups of people assign credibility and trust to knowledge claims located outside the established boundaries

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of science? This research question was the focus of a wide-ranging research project which began in 2019. Almost no-one anticipated the transformative potential of the pandemic events that unfolded a few months later. The COVID-19 pandemic, which undeniably changed our lives, completely redefined the general research landscape in which the project was to have been carried out. However, as the well-known adage goes, every cloud has a silver lining. The exceptional nature of the pandemic situation turned out to be an extremely interesting opportunity to address the research question mentioned above, since it brought out the processes we wanted to study even more clearly. In other words, the pandemic was a chance to shine the spotlight on the circumstances under which concerned groups of people challenge the legitimacy of techno-scientific expertise as the unique domain with which individual and public health issues and broader societal challenges can be responded to.

Contemporary practices contesting scientific knowledge claims and advice have recently been at the core of various scholarly and public debates, opening up space for a heated debate over the reconfiguration of the nexus between science, technology, democracy and society (see Armstrong & Naylor, 2019; Ball, 2017; Bory, Crabu, et al., 2022; Bory, Giardullo, et al., 2022; Crabu et al., 2023; Lynch, 2020; McIntyre, 2018; Pellizzoni, 2019). It is worth highlighting that questioning scientific knowledge is a multifaceted phenomenon cutting across a range of different issues and public concerns, such as institutional public science communication practices and public engagement models; the current role of digital technologies and social media platforms as information hubs; the demand for greater transparency in scientific research and its governance; and the relationship between scientific research, technological developments and social justice.

Hence, the questioning of science and techno-scientific expertise cannot be simply dismissed as a mere rebranding of old forms of scientific illiteracy or the product of alleged distorted media representation of science. But there can be no doubt that the COVID-19 pandemic has clearly shown how important the forms and practices of opposition to scientific knowledge are to the biomedical domains and public health in general. Since the beginning of the COVID-19 pandemic, a growing number of groups of concerned people have developed alternative knowledge claims regarding how to manage health and well-being outside the

scientific epistemic borders, thus questioning science-based advice and rules (e.g. physical distancing measures, mandatory use of personal safety protection devices, vaccine policies) implemented to combat the dissemination of the virus. They thus challenged the exclusive authority of scientific communities, biomedical institutions (e.g. health agencies and medical associations) and gatekeepers of truth (e.g. science journalists and public intellectuals) in interpreting the pandemic and deciding how to manage it. In so doing, they strongly questioned the legitimacy and suitability of science-based governance models in dealing with emerging societal issues.

In this respect, recent research has demonstrated that this critical, or at least distrustful, attitude to scientific knowledge and advice is more than simply a contingent reaction to the COVID-19 global outbreak and containment policies (Butter & Knight, 2023; Crabu et al., 2023; Prasad, 2022). Rather, during the pandemic, the strong and, to a certain extent, unprecedented public visibility gained by groups of people claiming legitimacy for action outside the boundaries of science was, in many respects, a kind of litmus test for a phenomenon—that is contesting techno-scientific authority—rooted in long-term social issues concerning: (1) the dynamics of public trust and mistrust in the ability of techno-scientific expertise to address and solve the potential unintended risks and (social and ethical) consequences arising from technoscience-driven innovations (see Beck, 1992; Oreskes, 2019; Weingart, 2023) and (2) the growing consensus among both ordinary people and communities of healthcare professionals regarding the utility of alternative models of caring and healing (Brosnan et al., 2018; Vuolanto et al., 2020). Consider, for example, how well-controlled diseases are breaking out once again in highly developed countries due to distrust of vaccination policies; or that, in 2018, the American Society of Clinical Oncology's second annual National Cancer Opinion Survey showed that nearly four in ten US citizens (39%) believe cancer can be tackled with alternative therapies such as enzyme and oxygen therapy, diet, vitamins and minerals alone (National Cancer Opinion Survey, 2018)—despite strong scientific evidence that patients with common cancers choosing to treat them with alternative medicine only are 2.5 times more likely to die of it than patients receiving standard cancer treatments (Johnson et al., 2018).

In fact, the history of science and scientific medicine is packed with, if not actually made up of, conflicts between different professional and social groups, some of which have been expelled from the institutional boundaries of prevailing scientific and medical communities (Woodward & Richards, 1977). Although alternative scientific and medical knowledge has been studied since the 1980s, particularly within the social studies of science field (see Collins & Pinch, 1982; Nowotny & Rose, 2011; Wallis, 1979), the prevailing perspective in social science research programmes and public debates is still that suspicion and distrust from an ‘irrational’ and ‘dangerous’ mindset (on this point see Harambam’s seminal critique, 2020a). In recent research, this view has also fed a widespread concern that the increasing inclusion of digital platforms in all our daily practices and routines has allowed deception and misinformation cultures to proliferate (Del Vicario et al., 2016; Vosoughi et al., 2018; West & Bergstrom, 2021; Zarocostas, 2020). Within this scenario, in various media contexts (both legacy and digital), academics, political analysts and policymakers worldwide have advocated for the reaffirmation of the centrality of the ‘light of reason’ as the sole guiding principle in both individual and public decision-making processes, defending it against what they see as an irrational and uncritical acceptance of fraudulent, counterfeit and inaccurate information. Accordingly, individuals or groups of people who question the monopoly of techno-scientific expertise, as well as its pertinence to both societal and technoscientific issues, are often accused of undermining the very principles of ‘Western’ scientific rationality through the dissemination of fake news, deceptive information and conspiracy theories.

In this interpretation, traditional epistemic institutions and gatekeepers of truth are losing their monopoly on public (health) issues, and in this process, so-called malicious agents—alternative healers, cult leaders and misinformed people—have begun spreading their own non-scientific claims and counter-knowledge. Accordingly, many analysts, institutionally recognised experts and members of scientific communities have argued that advanced democracies are falling into a state of emergency due to social media-based infodemics (Zarocostas, 2020), changes in the professional structure of scientific journalism and increasingly misinformed populations. In their view, this state of emergency takes the form

of open conflict between scientific experts, policymakers, business lobbyists, and concerned groups of people questioning the legitimacy of science's claim to define what *nature* and *society* are and how societies should be governed.

Whilst stopping the circulation of fraudulent or inaccurate claims is an urgent concern, analytically speaking what is most deserving of attention is the increasingly important role played by Western scientific institutions and their representatives in the governance of societal challenges which have become subject to contentious social and political dynamics. These dynamics recall the well-known paradox of scientific authority (see Bijker et al., 2009), according to which in contemporary times, demand for scientific guidance spans a wide spectrum of topics, encompassing areas such as energy production and genetically edited organisms (including humans). However, paradoxically, it appears that the greater the urgency in seeking scientific advice, the more sceptical policymakers, stakeholders and the general public are of scientific authority. Hence, at the core this paradox is the claim to the right of other forms of expertise, besides scientific knowledge, to exist and be mobilised in response to public issues, thus shaping a perspective by which true and useful knowledge does not necessarily correlate with scientific epistemology.

In this respect, current cultural perspectives questioning the monopoly of science are strongly stigmatised by various academics and public commentators, as was apparent during the COVID-19 pandemic in particular. These argue that a critical stance regarding science is inherently irrational and dangerous and, as such, must be opposed in order to preserve democracies and the well-being of our societies (Ball, 2017; D'Ancona, 2017; McIntyre, 2018). Thus, contemporary forms contesting the epistemic authority of biomedicine, and techno-scientific expertise more generally, have been framed as publicly devaluing the very concept of 'truth' and challenging 'the existence of reality itself' (McIntyre, 2018, p. 10). More particularly, in social and political studies exploring the changing relationship between expertise and society, this position is extremely evident amongst those cultivating a wide-ranging research current regarding the emergence of a 'post-factual/post-truth society' (see Farkas et al., 2017; Fuller, 2018; Giusti & Piras, 2021) as an era dramatically dominated by fake news-making processes and in which objective

facts are less influential in shaping public decision-making and individual choices than personal beliefs and individual experiences.

While the post-truth debate has revitalised discussions concerning the legitimacy and public implications of social studies in exploring scientific and expert knowledge, it should be recognised that reducing such a complex phenomenon to mainstream labels such as ‘post-factual’, ‘fakers’ or ‘anti-science’ can pave the way for a normative analytical strategy that seeks to distinguish different forms of knowledge by applying the same scientific rationality demarcation criteria. In our view, this analytical stance risks reiterating *naïf* accusations of irrationality without elucidating the existing social relations between science and other competing forms of knowledge and expertise, as well as neglecting the cultural and material conditions behind the emergence of a contentious relationship between science and concerned groups of people. Delving even deeper into this point, it is worth highlighting that a normative analytical stance risks assuming that any scholar writing about knowledge and people with a contentious relationship with science inevitably takes on one of the following two irreconcilable roles: ‘dangerous advocate of irrational claims’ or ‘upstanding gatekeeper of Western rationalism’. The former consists of legitimising allegedly anti-scientific stances, and the latter contributes to restoring the light of reason to its rightful place and uncovering the hidden dangers involved in questioning science and techno-scientific expertise. Hence, the idea that knowledge-making processes on the margins of science should be studied by adopting an agnostic stance—that is without passing judgement on their ethical value or assessing whether a given belief is ‘rational’ or ‘true’ according to prevalent scientific criteria—may be regarded with suspicion as a covert attempt to legitimise potentially dangerous and irrational mindsets.

This crucial point was recently re-examined by Jaron Harambam (2020a) in an exploration of contemporary conspiracy culture. In his book *Contemporary Conspiracy Culture*, Harambam seeks to adopt a symmetrical stance, addressing alternative forms of knowledge without explaining them through causal factors like cognitive biases, scientific illiteracy or emotional drivers. In this way, Harambam urges social scientists to agnostically consider the multifaced perspectives of people and communities supporting alternative knowledge with a view to

understanding the processes spawning controversies around certain claims and issues. In Harambam words, this can be done by ‘taking a stance without taking sides’ (p. 235). As the author clarifies, if ‘I may side with conspiracy theorists on *procedural* terms, I do not (necessarily) side with them on *substantial terms*’ (p. 238; author’s emphasis). In other words, it is the drivers that push people not to believe certain science-based claims—or at least to view them sceptically—not the content of the knowledge per se that are of interest to social scientists. Such a perspective, however, may pose a contradiction between what Harambam calls ‘normalization’—there is nothing wrong or deviant in the way social and natural worlds are understood outside the epistemic border of science—and ‘stigmatization’—knowledge production outside the borders of science is dangerous because it supports possibly deviant behaviours and undermines the relevance of technical and scientific expertise and science-based policymaking. In disentangling this contradiction, Harambam proposes to contextualise contemporary conspiracy culture within its ‘social, cultural, and political settings’ so that ‘the two supposedly contradictory developments of conspiracy culture (normalization and stigmatization) may not only be both true, but, paradoxically, may even be reinforcing each other’ (p. 10). In other words, a perspective by which both science and other competing forms of knowledge are analytically grasped without prejudice, and treated impartially, is crucial, i.e. it is not social scientists’ job to judge knowledge (scientific or otherwise) in terms of truth or falsity but rather to explain its emergence and stabilisation and, potentially, the socio-technical process through which bodies of knowledge acquire epistemic authority.

Against this backdrop, it might be said that this book is located within the same analytical framework elaborated by Harambam (2020a, 2021) but it widens its field of enquiry also to other, not (necessarily) conspiracist groups. What the book thus attempts to do is to overcome a definition of conspiracy theories that may be simultaneously too broad (as Harambam himself recognises that the conspiracy label encompasses many different things) and too narrow (not all alternative knowledge claims can coalesce in the conspiracy category). In this respect, the first focal point of this book is that contemporary science contestation practices play out at the epistemological level, as communities and groups of

concerned people shape and share knowledge claims while adopting an ambivalent relationship with science and various epistemic institutions. Different social values and objectives can shape mutual incompatibilities or incommensurable confrontations between scientists and those that contest their epistemic authority, while in other cases disagreement may only be partial.

A second focal point concerns the role played by internet-based digital, networked and social media technologies in sustaining communication processes in which interpersonal relationships allow people to share information and lay knowledge, and build communities as critical resources in practices questioning science. Indeed, digital and social media technologies cannot be considered merely communicative spaces with which to disseminate ‘alternative’, and ‘non-scientific’ knowledge and facts; they are also an interactional setting that co-shapes individual and collective subjectivation processes, future scenarios, mutual recognition and collaboration, as well as the collective actions of those who—for various reasons—do not precisely align with the prevailing scientific visions and representations of the world, as the COVID-19 pandemic clearly highlighted (Prasad, 2022).

By considering these two interrelated focal points, this book will show that science and competing forms of knowledge are not two well-bounded entities but rather two possible poles on a continuum in which the social, political and epistemological processes of defining the relationship between expertise, science, technology and society are located. In this way, the volume aims to take seriously Harambam’s recent and extremely urgent call (2020b) to Science and Technology Studies (STS) scholars to conduct fieldwork on science contestation practices and cultures, moving ‘beyond prevalent simplistic oppositions between science vs politics, facts vs opinions, information vs manipulation, solidarity vs freedom, public health vs economy, lockdowns vs viral explosion’ (Harambam, 2020b, p. 61).

Theoretically speaking, this book is primarily rooted in the STS field, and proposes an integrated perspective intersecting the Social Worlds Framework (SWF; see Clarke & Star, 2008) with the major analytical standpoints developed by Actor-Network Theory (ANT)—namely its agnosticism regarding who or what has agency—which generates a focus

on the relations made and remade between human and non-human entities forming part of the social world under examination (see Callon, 1984; Latour, 1987).

The SWF allows us to identify and investigate science-contesting cultures in collectivities, where relatively coherent sets of shared commitments, practices, norms and knowledge may operate through interactions and specific socio-technical arrangements. In this respect, by cross-fertilising SWF with ANT (see Chap. 2 by Federico Neresini), the volume will consider both the social and technological conditions behind science-contestation cultures, in order to grasp the ways in which scientific knowledge and science-based ordering processes are questioned by human-nonhuman assemblages. Within this theoretical framework, our aim is to mobilise an agnostic analytical positionality allowing us to set aside *a priori* assumptions about the nature of assemblages, causal conditions and the accuracy of actors' accounts. Thus, soliciting impartiality, this positionality aims to critically reconsider and overcome ingrained juxtapositions between truth/falsity, rationality/irrationality and science as neutral/science as revolutionary. The book will hence embrace the 'symmetry postulate' (see Lynch, 2017), recently re-examined in the STS field to suggest an analytical approach to examining knowledge-making practices without privileging any one kind of statement over others, or normatively labelling specific claims as true or false. As David Lynch has, in fact, argued:

The [...] contrast between 'objective facts' and 'appeals to emotion and personal belief' does not quite capture the challenge to science in the current era. Instead of an outright rejection of science and objectivity, what is involved is an effort to produce adversarial claims to objectivity and institutional support for those claims. (Lynch, 2020, p. 50)

Through this lens, science contestation practices—involving both human and non-human actors—are framed as an emerging outcome of networking activities shaping social worlds that are both enacted and transformed through intra-action processes (Barad, 2007). These processes can also re-configure the composition and conditions of concerned social worlds, thus shaping the knowledge and material background for

the emergence of new broad substantive arenas made up of multifold social worlds.

From this perspective, the aim of this book is to explore how this networking activity comes into being, which kinds of social worlds it constitutes, how social worlds come to be made up of human agents and (media) technologies as well as by segments of scientific communities and their opponents, how actors are enrolled into social worlds, how parts of social worlds can be re-assembled to form new ones, and how social worlds can temporarily achieve stability, shaping and sharing what we label 'refused knowledge' (RK), i.e. a body of knowledge partially or totally refused by institutional and scientific authorities. Accordingly, the volume explores both how RK is produced as 'matters of fact', circulated and entrenched, but also how it can be reworked as 'matters of concern'.

In actual fact the notion of refused knowledge embodies the theoretical and reflexive approach pursued within this book. When we started the fieldwork from which this book derives, we engaged in in-depth discussion within the research team about the 'right words' to use in talking about current challenges to science. In our search for the most suitable words, we opted to agnostically unfold the process of shaping and stabilising refused knowledge, that is, a body of knowledge around which some segments of society find a common space for action and sense-making by bringing together their issues of mutual concern. We refer to this space in terms of 'communities based on refused knowledge' or, in short, 'refused knowledge communities' (RKC), precisely to emphasise our commitment to not normatively labelling people who distrust science, and to not passing judgement on their ethical values and beliefs. Hence, in this book we make the case that it is not RKC's apparent 'exoticism', danger, even weirdness which makes them worthy of study. Rather, what makes RKC a relevant research object for social scientists revolves around the conditions under which RKC outline different kinds of social realities, and how they make sense of them without reverting to techno-scientific expertise. By framing RKC as social worlds, we avoid assigning a historical and predetermined hegemonic position to institutional scientific paradigms, and thus we also avoid defining emerging knowledge-making practices in terms of their difference or distance from prevailing scientific paradigms. This allows us to reverse the dominant

perspective that frames competing forms of knowledge and contestations of science in terms of aberrant and deviant phenomena, thus considering the discourses, practices and resources—both material and relational—by which RK can become trustworthy and reliable in the eyes of concerned groups of people in depth.

Overall, the volume is based on an extensive three-year mixed-method empirical research into four Italian RKC's especially concerned with health-related issues, namely:

- the Pro-vaccine choice¹ RKC which opposes mandatory vaccination and engages in work to promote information on the risks of vaccination and support families suffering alleged vaccine damage;
- the Five Biological Laws RKC encompassing the followers of the so-called Germanic New Medicine, a complex system of knowledge—refused by allopathic practitioners as lacking a scientific basis—that purports to be able to cure cancer, among many other diseases;
- the Alkaline water RKC, promoting alkaline water consumption and an alkaline diet to counteract the risk of metabolic acidosis, which is held to be responsible for many diseases, including cancer and diabetes;
- the Stop Fifth Generation (Stop-5G) RKC, whose members are citizens engaged in opposing the fifth-generation (5G) standard for broadband cellular network rollout, which is considered to be the primary vector of electromagnetic hypersensitivity and other diseases, such as cancer.

These four RKC's share the following characteristics: (1) the rejection of all or part of the stabilised explanations offered by science of many health- and illness-related phenomena; (2) the production of formalised (or formalisable) knowledge capable of offering answers to certain health, care and general well-being problems; and (3) a major focus on health issues, with a strong commitment to boosting individual agency and responsibility in managing well-being. Our overall research design was

¹In Italy this community self-identifies in English as 'free vax'. While in other research (see Bory, Giardullo et al. 2022) the label 'free vax' was used, to avoid obfuscating the emic jargon, in this volume we have preferred the label 'pro-vaccine choice' since the term 'free vax' is not commonly used in English and is potentially misleading.

elaborated before the whole field of inquiry was disrupted by the COVID-19 pandemic and was then reconfigured in the pandemic context, which can be considered emblematic in underlining the reciprocal contentious relationship between RKC, on one hand, and the prevailing scientific institutions and their representatives, on the other.

Empirical data was gathered through an articulated research design encompassing: an extensive digital ethnography within several online settings (such as Facebook, YouTube, webinars and instant messaging platforms; participant observation of key public events); 70 qualitative interviews with RKC members; and a quantitative analysis of a large dataset of all articles related to the four RKC published by eight major Italian newspapers. Relying on this large empirical data set, the book investigates and critically examines these four RKC, their narratives and public discourses currently circulating in Italy, as well as the forms taken by challenges to the prevailing scientific epistemology.

The book consists of nine chapters, with a concluding remark section opening up the debate about the relevance of exploring refused knowledge to a reconsideration of our understanding of the relationship between science, technology and society.

The second chapter, by Federico Neresini sets the conceptual and analytical frame for the subsequent chapters. Recalling a number of epistemological debates deeply rooted within the STS tradition—such as those concerning the relationship between the researcher and who/what is analysed (positionality), the process through which every element in a network is continuously constituted (relationality), and the fact that when something is defined, its counterpart is also constituted (reciprocity)—it supplies a general framework within which the symmetry principle guided our research. Thus, it discusses the substantive reasons behind the RKC notion in full. The chapter then elucidates the theoretical approach we deem best suited to studying the RKC, i.e. an integration between the SWF and certain concepts developed by ANT, including discussing how and whether their cross-fertilisation is possible and useful in exploring the current challenges to science. The third chapter by Paolo Volonté highlights how endorsing and embracing a body of refused knowledge is much more than a merely cognitive act. Indeed, refused knowledge enacts the shaping of communities of people engaged in a contentious

relationship with science, thus involving interpersonal bonds, networks and social relations that exceed mere instrumental objectives and shape a feeling of belonging. Embracing refused knowledge and taking part in a refused knowledge SW can be a significant event in individuals' personal life trajectories and one which is not ascribed but acquired through a biographical transition. In biographical trajectories, there is often a period of transition from believing in socially recognised and institutionalised systems of knowledge to believing in an alternative one, refused by the dominant (scientific) community and accepted by a minority. Belonging to a refused knowledge community is a milestone in a personal biography that often involves costs or, in any event, important changes in work and social relations, political choices, health choices and body care practices, etc. It is, therefore, not simply a cognitive, but also an emotional, material, behavioural and social transition enacting collective identities. This last point is further developed in Chap. 4 by Paolo Bory, who investigates how the RKC's reiterate and share a common background shaped around founding narratives, anecdotes and 'founding fathers', which constitute the building blocks of their collective identity. In particular, the chapter provides an understanding of how narratives and tropes together contribute to the shaping of a common set of cultural, epistemological and 'stylistic' elements characterising the relationship between RKC's, science and society.

Chapter 5, by Simone Tosoni, adopts an ecological perspective on the digital sphere to address the media-related practices through which RKC's narratives and belief systems are produced, stabilised and occasionally transformed, sometimes radically. Focusing on the Stop-5G RKC, the chapter aims to shed light on the close relationship between these discursive practices, the knowledge they produce and the organisational forms taken by social worlds claiming that non-ionising electromagnetic radiations have dangerous non-thermal effects. In particular, it shows that, during the pandemic crisis, the Stop-5G RKC transformed its discursive practices (and, consequently, its shared knowledge and narratives) from a 'scientific patchwork' storytelling approach—based on a rigid definition of borders and the selection of scientific sources—to a 'syncretic patchwork' one based on a combination of different and sometimes conflicting

discursive sources (e.g. scientific knowledge, folklore, new age spirituality and conspiracy theories).

The issue of how specific social configurations can sustain the process of conferring credibility on RK is addressed by Ilenia Picardi, Luca Serafini and Marco Serino in Chap. 6. By combining the theoretical and methodological framework of Social Network Analysis and the SWF, it investigates the processes of association at work within the discursive universes of RKC, aiming to uncover the discursive configuration structures which build, maintain and legitimise different forms of refused knowledge. Hence, Picardi et al. make the case that addressing the issue of how people actually give credibility to health-related refused knowledge inevitably challenges researchers to consider fundamental issues about the way they recombine epistemic stances and beliefs about the social and political organisation of science, and of biomedicine-related fields.

Following this line of inquiry, in Chap. 7, Stefano Crabu sheds light on the RKC's contentious relationship with the political conditions under which biomedical knowledge is shaped and mobilised by health professionals. In so doing, it elucidates how this contentious dynamic is entangled with the ways in which RKC confer credibility and reliability on refused knowledge. Hence, the chapter shows that RKC are not merely concerned with challenging the content of scientific and biomedical knowledge but also with questioning its epistemic, professional and economic roots: that is RKC argue that claims and knowledge elaborated and enacted in the context of biomedicine, and the life sciences in general, are entangled with particular social, political and material interests, and therefore not to be believed, or at least to be treated with scepticism. Hence, conferring credibility on refused knowledge involves not only assumptions about trust and truth, but also a critical scrutiny of how the State and related governmental bodies, medical agencies, life scientists and health professionals control, manage and reshape the very vital capacities of human beings as living bodies. This critical scrutiny implies the mobilisation of certain arguments that can be specific to a single RKC, or cut across multiple social worlds, thus generating a shared discursive arena.

The process involved in enacting broad discursive substantive arenas (see Clarke & Star, 2008) is explored in Chap. 8 by Barbara Morsello,

Federico Neresini and Maria Carmela Agodi. In so doing, it highlights the role played by both human and non-human agents (such as the technologies mobilised to counteract the spread of Sars Cov-2 and the actors considered experts by RKC followers) in enacting counter narratives about the COVID-19 pandemic, so as to make sense of the global emergency according to a body of refused knowledge. Hence, the chapter illustrates how these counter narratives progressively empower RKC to collaboratively act within a broad discursive arena, fostering public dissent against public health policies. Indeed, RKC permeate public discourses about emerging societal issues in depth, also attracting the attention and concerns of both policymakers and media operators.

In Chap. 9 Paolo Giardullo—shifting the analytical focus to how refused knowledge circulates in the wider public sphere—explores how Italian newspapers cover and frame issues and concerns raised by RKC. In so doing, Giardullo focuses on the issues advocated by the four concerned RKC in two interconnected ways: a quantitative presentation of coverage through a longitudinal analysis of the whole body of articles published by eight Italian major newspapers from 2010 to 2022, and a qualitative account produced by means of content analysis addressing the issue of the institutionalisation of scientific knowledge through the delegitimation of RKC claims. This analysis highlights the ways in which media narratives about refused knowledge can play an ambivalent role both in sustaining the public legitimacy of science and in opening new spaces for public dissent regarding techno-scientific expertise.

Finally, in Chap. 10 Barbara Morsello offers a reflexive account of the overall fieldwork conducted by the research team into the four RKC. A reflexive account is particularly important here as refused knowledge followers share a widely held belief that academics in general act as spokespersons for epistemic regimes that they see as responsible for ostracising their knowledge within the public sphere. An additional element making a reflexive account even more urgent is that RKC followers may hold beliefs, values, assumptions and political views in sharp contrast to those of the researchers engaged in the fieldwork. Against this backdrop, Morsello's reflexive stance explores the challenges that researchers engaged in studying the concerned RKC face in their attempts to negotiate and conduct interviews with refused knowledge followers.

Overall, the book suggests that framing the contestation of the epistemic authority of science in terms of generalised anti-science campaigns or a current deviant irrational ‘zeitgeist’ may be less helpful than treating RK as a specific way of knowing the world and of producing specific claims in a complex relationship with prevailing epistemic institutions. RK is shaped and mobilised through everyday experience, procedural argumentation and, sometimes, by mobilising the argumentative repertoires and explanatory rhetoric pertaining to science by means not only of ‘experiential experts’ but also of institutionally recognised experts who publicly present and legitimise pieces of RK, or question consolidated scientific matter of fact as an object of public concern. Thus, far from assuming a simple dichotomy between ‘rational science’ and ‘irrational anti-science’, what the book makes apparent is the specific mobilisation and selective use of symbols, grammars and experiential observations, as well as certain scientific authority procedures to co-produce a social order on the basis of RK rooted outside the epistemic borders of science.

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2

Can We Look at Refused Knowledge Differently?

Federico Neresini 

2.1 Introduction

Recalling that the distinction between science and society constitutes a kind of original matrix from which a long series of other distinctions—which have oriented and fed theoretical reflections and empirical research on knowledge in the context of modern Western culture—were later derived may somehow appear scholastic, and thus obsolete, but it is nevertheless important. Some well-known examples include dichotomies such as science/non-science, science/lay or popular knowledge, science/anti-science and science/scientific illiteracy.

Understanding why the science/society distinction is so deeply embedded in our culture, and so prolific, goes beyond the scope of this study. Fortunately, a number of STS scholars have made a great many contributions in this regard, amongst which *We Have Never Been Modern* (Latour,

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F. Neresini et al. (eds.), *Manufacturing Refused Knowledge in the Age of Epistemic Pluralism*, https://doi.org/10.1007/978-981-99-7188-6_2

1991) occupies a leading position. In this introductory chapter, I will therefore limit myself to acknowledging the existence of such a distinction and the strength of its roots, a strength which continues to this day, although signs of its weakening are increasing and continuously emerging from the recent post-truth debate, for example (Fuller, 2018; Lynch, 2017; Sismondo, 2017).

What needs considering here is the main consequence of the science/society distinction on the analysis of what we have defined in the introduction as *refused knowledge* and the social worlds of which it constitutes the main reference, i.e. those we call *refused knowledge communities* (RKC). This distinction has progressively generated a negative qualification of most types of knowledge falling outside science—including refused knowledge itself—albeit labelling these in various ways, such as weakness, approximation, irrelevance, falsehood, distortion, contamination and even danger. Separating science from society has therefore generated a twofold tendency to homogenise the differences between the various types of non-scientific knowledge by treating them as residual to scientific knowledge and evaluating them negatively.

Non-scientific knowledge constitutes actually a variegated universe, not only because it encompasses visions of the world that are often very distant and, in any case, never fully overlap, as they are rooted in a highly varied spectrum of practices, but also because its attitude to science is a very varied one.

Take, for example, common knowledge, sometimes also referred to as lay, popular or vernacular knowledge (Eglash et al., 2004). Wynne (1996) initially defines this in opposition to expert knowledge, but he later clarifies that its counterpart is not science but rather the ‘social assumptions and models framing its objectivist language’ (p. 59). Lay knowledge, therefore, is not just all knowledge lying outside science but rather local, contextual and informal knowledge that is more flexible than science, by which I mean that it can capture aspects and changes which the more universal and hence more abstract scientific understanding usually cannot. In enabling individuals to exert ‘adaptive control’ (Wynne, 1996, p. 70), lay knowledge is extremely useful and relevant to the everyday life context. It has also been observed that, within such a context, the importance of personal experience is growing as a criterion with which to assess

the relevance and reliability of knowledge claims; thus, ‘the truth is *in* there’ rather than *out* there, as it must be proven ‘in the self, in personal experiences and feelings, in subjective judgement, [and] in individual memory’ (van Zoonen, 2012, p. 57).

All the same, lay knowledge is not overtly opposed to science on the ground; but this is not the case of science-related populism, another type of knowledge that lies outside science.

In fact, science-related populism has been defined as an antagonist perspective based on the supposition that there are virtuous ordinary people who oppose the illegitimate claims made by a non-virtuous academic elite (Mede & Schäfer, 2020). In this view science-related populism is thus a morally driven set of claims—generally not very widespread, unlike political populism (Mede et al., 2022)—in contrast with the local and informal lay knowledge to which common people turn for answers to practical problems. Recognising the differences between consolidated popular knowledge traditions and ‘the claims of an actress that vaccines cause autism’ would therefore seem possible (Oreskes, 2019, pp. 62). While the latter pertains to a repertoire of claims accompanying a pre-conceived stance of moral superiority that rejects science as part of the establishment, the former represents a possible alternative to science with which a collaborative relationship is sometimes possible. This is why traditional knowledge is not always rejected a priori by science and some of its parts can be seen as open to reconfiguration within scientific knowledge, albeit with some reluctance.

This is what happens, for example, with complementary and alternative medicine (CAM), which is regarded as a set of knowledge derived from popular traditions and/or their more recent re-elaborations, often through a syncretic process which reorganises some elements of different cultures into a new organic whole. In fact, science sometimes recognises that CAM has the potential to address certain pathologies and some of their symptoms which modern biomedicine cannot provide answers to (Brosnan et al., 2018). Thus, for example, for the US National Center for Complementary and Integrative Health, a non-mainstream practice used together *with* conventional medicine is considered ‘complementary’,

whereas a non-mainstream practice—which may even be the same one—used *instead* of conventional medicine is considered ‘alternative’.¹

However, the difference between complementary and alternative knowledge remains nebulous and non-definitive. Knowledge claims not validated scientifically and supported by unlikely subjects, i.e. those lacking adequate socially recognised credentials, if not openly dishonest, are used in everyday life contexts to respond to sense-making needs revolving around coping with highly uncertain situations that the most legitimate knowledge—primarily science—fails to counter.

This was frequently observable during the pandemic.

Moreover, alternative knowledge is regarded as a synonym of counter-knowledge and this is indeed sometimes the case. However, counter-knowledge is marshalled mainly when groups and people mobilise around specific issues, giving rise to a *counter-public* (Hess, 2016). This again implies many different configurations of the relationship with science, ranging from demands for partnership with scientists to fill a knowledge gap relating to issues that are important to laypersons (see the concept of *undone science*; Hess, 2016) to situations in which the latter decide to ‘do it themselves’, as in the case of popular epidemiology initiatives, although some scientists and/or physicians are sometimes also involved in this (Allen, 2003; Brown, 2007; Krimsky, 2000).

What lies outside science, therefore, is a multifaceted complex of varying types of knowledge with differing attitudes to science. But what all these non-scientific types of knowledge share is a condition of inferiority to science.

From an initial distinction between scientific knowledge and social knowledge, an only apparently obvious semantic shift has therefore reduced all forms of scientifically unaccredited knowledge to a single category—that of non-science. At the same time, the definition of this category as residual to science has ended up devaluing it.

¹ <https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-health-whats-in-a-name>

Consequently, on one hand, both common and academic discourses tend to treat non-scientific knowledge as subjective and thus often false, if not downright fraudulent, on the other, knowledge labelled scientific is thus objective and true, precisely because it has nothing to do with the heterogeneous context of its production and use. It is true because it is a-historical and a-social. Similarly, a lack of scientific literacy is a deficit to be dealt with through appropriate education and communication initiatives or, at best, through dialogue and involvement (Bucchi & Neresini, 2008; Callon, 1999; Wynne, 1995).

Non-science is therefore depicted as a desert in which all differences are levelled out—a single great void to be filled, an empty counterpart to the fullness of science.

This negative connotation sometimes emerges from the labels used for some types of non-scientific knowledge, such as junk science, pseudo-science, fringe science and science at the margins. In all these cases, the boundary work carried out to deal with the demarcation problem (Gieryn, 1983) clearly relies on rejecting and devaluing such types of knowledge.

Even more interesting is that this negative portrayal of non-scientific knowledge tends to emerge even when its relevance and thus its value are acknowledged. All the adjectives with which we seek to non-negatively define the various types of non-scientific knowledge run the risk of connoting them negatively. That is, differentiating themselves from science inevitably takes them to the opposite side and in a condition of inferiority from which they must be protected. Indeed, current perspectives adopting terms such as *complementary*, *alternative*, *traditional* and *heterodox* to contrast with *conventional*, *orthodox* and *official* confer intrinsic epistemic dominance to science. Given the persistence of the underlying science/society dichotomy, these binaries tend to generate inaccuracies, blind spots and simplistic representations of both science and other forms of knowing, as we have seen in the case of CAM.

Is an approach to the different kinds of non-scientific knowledge which avoids falling into the semantic traps set by the science/society distinction possible?

2.2 Labelling, Positioning, Knowing: The Symmetry Principle in Exploring Refused Knowledge

One approach to the above quandary is starting with the labelling issue. Deciding how to name what we are interested in is no trivial matter. In fact, the label we use says a great deal about our perspective on the matter in hand—about its collocation within a classification system that defines its relationship with us and with other entities, as well as about what is important and unimportant to us. Naming is part of a classification process, i.e. the way we accord categories to ourselves, and others, which determine the identity, relevance and behaviour of everyone and everything (Bowker & Star, 1999). Therefore, naming is not a neutral act of description but a bidirectional process of construction. The names we give to what we are talking about have effects on both the *object* under observation and the subject observing it. The ‘looping effect’ (Hacking, 1999) operates contextually on the observed and the observer; they are mutually co-constructed, as STS has repeatedly noted.

There is certainly nothing new about knowledge as a question of positioning. The so-called *linguistic turn* in twentieth-century philosophy underlines that reality, or, even better, what we refer to as such depends on our language and, therefore, our point of view. At the same time, the sociology of knowledge in general and STS in particular are both constantly engaged in analysing how knowledge results from a process which is always embedded where the knower is located.

Like anthropologists, STS scholars are also very aware of the ‘native’s point of view’ issue (Geertz, 1983), i.e. that the way we understand how scientific knowledge is constructed depends on our perspective on it. This is not solely the core quandary in laboratory studies, as Latour and Woolgar discuss in depth in the introduction to *Laboratory Life* (1986), but has been addressed on many other occasions and within various contexts, such as at the crossroads between STS and post-colonial studies (Banu et al., 2017; Harding, 1998, 2008; Law & Lin, 2017; Verran, 2001).

The *positionality* of any knowledge claim also plays a pivotal role in feminist thinking on science. Haraway (2018), for instance, pointed out

that not only is ‘science [...] the result of located practices at all levels’ but also that ‘location is not the concrete to the abstract of decontextualization. Location is the always partial, always finite, always fraught play of foreground and background, text and context, that constitutes critical inquiry. Above all, location is not self-evident or transparent’ (pp. 36–37). Thus, being aware that all knowledge is situated and depends on a specific point of view implies that the ‘god trick’ does not work and that choosing a partial perspective is the necessary premise to achieving ‘an objective vision’ (Haraway, 1988, p. 583).

The concepts of *standpoint epistemology* and *strong objectivity* are also relevant here. These were developed by Harding to show that not only does a diversity of perspectives enrich scientific enquiry, but it also reinforces it, thus transforming the unavoidable influence exerted on scientific knowledge by individual values, experiences and social positions into an epistemological resource (Harding, 1986). At the same time, in her concept of ‘transformative interrogation’ Longino (1990) showed how inescapable individual prejudices potentially spawn a collective objectivity, and Fox Keller’s criticisms of the ‘dream of a science completely objective’ based on the reductive equivalence between ‘scientific and objective, on one hand, and masculine on the other’ suggests that both are a disputable assumption designed to maintain the illusion of a neutral point of view on reality in the search for objectivity (Fox-Keller 1985, p. 88).

Moreover, in many ways, feminist analysis of science invites us to focus our attention on another significant aspect in our efforts to define an adequate point of view on RKC, one that can be encompassed within the term *relationality*, as feminist scholars have repeatedly emphasised the relational character of all the entities—human and non-human—involved in the networks from which knowledge emerges. Consider, for example, the idea put forward by Barad that what we refer to as ‘interaction’ should be replaced by ‘intra-action’ to stress ‘the mutual constitution of entangled agencies’ (2007, p. 33). Thus, instead of assuming that separate singular actors precede interaction, intra-action enables these actors and their agency to be configured as emerging effects of the relationship between them: ‘agencies are only distinct in relation to their mutual entanglement; they don’t exist as individual elements’ (Barad, 2007, p. 33). This is the case for ‘all the entities in technoscience’ which

‘are constituted in the action of knowledge production, not before the action starts’ (Haraway, 2018, p. 30).² However, whilst relationality is deeply rooted in many STS approaches, it undoubtedly constitutes the hallmark of actor–network theory (ANT). This is clearly recognisable in the work of its founders and is summarised in statements such as ‘reality is a process’ (Callon, 1986, p. 207) and ‘Technology is society made durable’ (Latour, 1991).

Relationality also allows us to highlight the complementarity or, better, the *reciprocity* of the output of classification mechanisms.

Just as a border defines the presence of two separate but neighbouring territories, two territories necessarily imply the presence of a border, and any boundary work involves constructing and maintaining the two areas, with each distinction thus defining an identity and its alter ego. This is the ‘topological’ character of the assemblages we are interested in, where both the disposition of entities and their identities depend on their relationship (Law, 1999). Thus, science and non-science are always reciprocally established, i.e. the former cannot exist without the latter and vice versa. Likewise, lay knowledge cannot exist without expertise, but the latter acquires meaning and social identity only as a counterpart to the former.

But reciprocity does not automatically mean distributing epistemological resources equally (i.e. everything—whether material, symbolic or relational—that plays a part in the knowledge claim legitimisation process) and hence the epistemic authority from which the power to define the situation or to be seriously considered is derived. In other words, reciprocity does not correspond automatically to symmetry, because the latter requires recognising the same epistemological relevance, if not the same dignity, to both sides (see also Chap. 10 by Morsello in this book).

As is well known, the symmetry principle proposed by the Edinburgh School (Bloor, 1976/1991) is designed to provide an alternative epistemological perspective to the sociology of scientific knowledge, with a view to overcoming the so-called *sociological immunity* of science. This

²The relationship that generates reciprocally the researcher and to the *object* of his/her attention has been discussed and analysed by many STS scholars. See, for example, the ‘enacting’ and ‘never alone’ concepts developed by Mol in the case of medicine (2002) and the discussion of epistemology in a post-colonial perspective, as done among others by Kenney (2015).

means abandoning the epistemic privileges associated with science when science is considered true, rational and working successfully, or all the features that simply guarantee that there is nothing to understand about science, that is, that scientific knowledge is true and there is thus nothing to explain. On the contrary, in exploring science in the making, STS scholars point out that what is at stake in the scientific enterprise is less discovering facts that pre-exist in nature than translating local evidence into generally accepted scientific facts. In other words, the STS perspective is about explaining why, how and through which social arrangements the findings generated by a specific research group in a peculiar context (e.g. a laboratory) at a particular time can become universally accepted facts.

Within this perspective, the social sciences can add their interpretative value only if our approach to science and non-science is free of prejudice, ensuring that both are treated impartially, i.e. given the same relevance and dignity as objects of enquiry for social scientists. In its broad meaning within the STS field, symmetry can thus be seen as an attempt to re-establish epistemological equality, even when a distinction does not configure an equitable distribution of epistemological resources between concerned actors.

Furthermore, thanks to the principle of symmetry, not only do we give equal epistemological dignity to scientific knowledge and to that refused as non-scientific, but the reciprocity and potential inequalities regarding who knows and what is known in the cognitive relationship are also considered. Thus, the *principle of generalised symmetry* can be seen not only as an attempt to give both humans and non-humans the same relevance within the processes by which actor-networks are assembled (Callon, 1984) but also as an opportunity to rearrange the epistemological distribution of power between researchers and actors in the field, i.e. between observer and observed (Waytt, 2008). Applying the principle of symmetry therefore constitutes a useful premise on which to avoid assuming a privileged position within the knowing relationship, including when this privilege is based on prejudices of a normative nature, in line with the arguments of feminist and post-colonial critics too.

As in ANT, the symmetry principle also works like a 'machine for waging war on essential differences' (Law, 1999, p. 7) produced by applying

distinctions such as human/non-human, science/non-science, truth/false and so on and also observer/observed or knowing subject/known object. In other words, seeking to be symmetrical accords no privileged point of view to the researcher—knowledge remains the fruit of a process that depends on the positions of the actors taking part in it and thus on the classification systems, with their labels, that are adopted from time to time. This is why ‘nothing comes without its world [but] location is also partial in the sense of being for some worlds and not [for] others’ (Haraway, 2018, p. 37).

However, the post-truth debate that has recently developed within STS has revealed the existence of at least three different ways of using the concept of symmetry (Pellizzoni, 2019), its central role in the STS field from the outset notwithstanding. The first of these essentially accepts criticisms from scholars outside STS and invites them to accept that, albeit involuntarily, the application of the symmetry concept has favoured the affirmation of post-truth at an ontological level and its appropriation by those self-identifying as right wing who use it to delegitimise any scientific knowledge which goes against their interests (Collins et al., 2017, 2020). The second, by contrast, rejects these criticisms and sees them as based on what it views as a misleading reconstruction of the principle of symmetry for which it would be incompatible with the recognition of the validity of scientific facts (Lynch, 2020; Sismondo, 2017).³ Finally, the third reverses the terms of the question, arguing that STS must indeed be questioned but for reasons which are diametrically opposite to those of their detractors. This position is most radically supported by Fuller (2018), for whom the advent of the post-truth era is a positive demonstration that even minorities are learning to question established power and thus ‘a triumph of democracy over elitism’ (p. 181).

These post-truth controversy stances each correspond to different approaches to the principle of symmetry. For the first, the different knowledge claims must be considered equivalent on the ontological level in the sense that they have the same epistemological value. For the second, symmetry is a methodological move that suggests considering the

³In some ways, this echoes the so-called science wars when the *Sokal hoax* was interpreted as proof of the groundlessness of a relativist approach to scientific knowledge (Hilgartner, 1997).

different claims as if they were equivalent, without implying that they are or are not true. For the third, symmetry is rather to be understood as a political strategy with which to rebalance the various groups' unequal distribution of epistemological resources, to define the situation and thus the very rules of political confrontation. For the latter, the principle of symmetry is therefore neither an ontological nor a methodological option but a political move offering minorities greater potential for debate with the majority.

Taking a cue from this internal tripartition of the STS debate allows us to further clarify how the concept of symmetry can be used to improve analysis of RKC.

There are at least three good arguments in favour of the second option, i.e. the methodological one.

Firstly, interpreting symmetry as a methodological orientation allows us to avoid having to decide whether 5G is really harmful to health, for example, or whether alkaline water really serves to restore our psycho-physical well-being. This is not our job, and it goes without saying that by so doing we can remain faithful to the original STS mandate—understanding how what we treat as scientific knowledge is built, consolidated and possibly decays—rather than trying to establish whether or not it is an objective representation of reality.

Secondly, treating different epistemologies as if they were equivalent rather than actually equivalent puts us in the best position to understand the construction processes used in both scientific and non-scientific knowledge, as this takes for granted neither the goodness nor the soundness of either.⁴ As a consequence, 'embracing epistemic democratisation does not mean a wholesale cheapening of technoscientific knowledge in the process' but, rather, it is a matter of showing that the statement 'It could be otherwise means very rarely that it could easily be otherwise' (Sismondo, 2017, p. 3). That is, claims require a wide array of resources—material, discursive or relational—if they are to be accepted and ready to use.

Thirdly, the methodological option averts the risk—to which, by contrast, the political option exposes us—of not clarifying whether this

⁴ See also Chap. 3 by Volontè in this book.

symmetry concerns the epistemological or the ontological level and, therefore, of finding ourselves enmeshed in the post-truth controversy without drawing great benefits from it in analytical terms. The most appropriate approach to the issue of relativism to our point of view here and for our purposes is, in fact, Law's, because it constitutes the most general framework of reference and of longest tradition encompassing the more specific and recent post-truth debate. Indeed, Law underlined that 'To accept the reality of epistemological relativism and deny that there are universal standards is not to say that there are no standards at all: and neither is it to embrace moral or political relativism. As Richard Rorty so well demonstrates, the either/or postulated by those committed to absolutism (either absolute standards, or no standards, epistemological or moral) is a false dichotomy. Locally we may seek to distinguish truth from power, persuasion from force, and what is right from what is wrong' (Law, 1991, p. 5).

In a nutshell, 'Symmetry does not preclude noticing differences between the contending parties, their backgrounds, commitments, and arguments, but it does discourage using familiar, and all-too-easy, arguments to dismiss one or another position as irrational, ignorant, or dishonestly motivated' and, at the same time, 'This is not so much a policy of interpretive charity as it is a strategy for gaining insight into the practical actions, discourse, and institutional supports that give rise to and sustain the resilience of such public controversies' (Lynch, 2020, p. 58).

This idea also corresponds with Latour's call for a shift from 'matter of fact' to 'matter of concern' (Latour, 2004). This means not assuming that objective scientific truth is valid per se but rather taking actors' points of view seriously and recognising that what is most relevant for social scientists is the network of relationships between interested actors and that it is within such networks that what is objective and what is not is defined, including what is to be taken on board and what is to be excluded.

On the basis of the above, the *refused knowledge community* label constitutes a chance to talk about social worlds bringing together people who feel they share knowledge refused by science and by the majority of other people. This helps us to take a stance with which it is easier to escape the constraints and biases usually posed by the science/society distinction. At the same time, it frames our analysis in terms of relationality and

reciprocity and fosters respect for the symmetry principle. However, we should not confuse the methodological assumption of equidistance with an impossible epistemological neutrality, i.e. the existence of a privileged observation point devoid of conditioning.

RKCs are made up of people who feel on the ‘wrong’ side of knowledge because they are seeking to attribute legitimacy to claims that are considered false, unfounded or deviant by the gatekeepers of institutional knowledge. This claim cannot be simply defined as alternative or even complementary, the fact that these two adjectives highlight features that also pertain to refused knowledge notwithstanding. Those who do not identify with the scientific frame often try to propose an alternative system of knowledge and, at the same time, previously refused knowledge is sometimes integrated into the scientific corpus through processes of boundary reconfiguration. This is true of acupuncture, for example, and some of the therapeutic principles deriving from herbal medicine or some traditional forms of body manipulation later acquired by physiotherapy.

Moreover, the words ‘alternative’ and ‘complementary’ tend to echo the dominant scientific position, attributing less value and less solidity to other forms of knowledge, on one hand, and assuming science’s power to define situations, on the other, both of which supporters of non-scientific knowledge lack. Talking about refused knowledge, by contrast, allows us to stress that—as with conspiracism—it ‘can hardly be understood by its inherent or substantial characteristics, but only by the fact that it has been labeled as such’ (Harambam, 2020, p. 25).

It is more than a matter of finding an appropriate name, however. We also need to find a theoretical framework that allows us to analyse RKCs coherently with the name we have chosen for them.

2.3 Point of View as a Matter of Theoretical Framework

We have already mentioned Haraway’s (2018) argument that ‘Nothing comes without its world’. We now also need to consider the second part of her sentence: ‘so trying to know those worlds is crucial’ (p. 37).

So what is the theoretical framework most appropriate to the analysis of RKC's?

There are at least two promising candidates: the social world framework (SWF) and ANT. There are many reasons for this choice, but the most important relate to their epistemological congruence with what we have discussed as regards positioning, relationality, reciprocity and symmetry. Both SWF and ANT are fully consistent with symmetry and relationality. On one hand, they argue for the importance of considering all the actors involved in the processes of building, shaping and stabilising knowledge claims with no preconceptions regarding their truthfulness, rationality or objectivity. On the other hand, they share the idea that knowledge is not a static description of reality but the emerging result of ongoing processes to which many heterogeneous actors contribute and on which they also depend. These actors include researchers, whose positioning is part of the constitutive relationship that defines them and the *objects* they study.

Of course, SWF and ANT offer a range of concepts which cannot always and wholly be coupled as equivalent. However, I believe that we can benefit from what they jointly offer to understand the RKC's by means of a number of considerations.

The concept of *social worlds* itself provides solid premises for the recognition of the relational character of knowledge because they are defined as 'universes of discourse', i.e. 'shared discursive spaces that are profoundly relational' (Clarke & Star, 2008, p. 113). The focus, therefore, is on meaning-making processes in which many actors—individuals and more or less organised groups—perform collective action while also working with shared objects. Within the SWF perspective, what counts as meaningful clearly depends on its embedding in a specific social world, and this tends to be 'particularly attentive to situatedness and contingency, history and fluidity, and commitment and change' (Clarke & Star, 2008, p. 113). As a consequence, SWF is intrinsically relational and symmetrical and avoids attributing epistemological pre-eminence to any specific point of view.

At the same time, SWF endorses an *ecological gaze* (Star, 1995) not only because each social world relies on the relationships between many different elements but also because each social phenomenon requires

contributions from and interactions between many social worlds.⁵ This ecological organisation of social worlds around an issue of mutual concern and commitment to action is regarded as an *arena*. In our case, this means that RKC's cannot be properly analysed without considering the ecology of the relationships in and through which they are established and shaped. In other words, RKC's are what they are and act as they act because they participate in a network of interactions that mutually define who and what is involved. After all, the very definition of RKC's implies reciprocity between those who feel they belong to a social world that shares knowledge refused by others and those who consider such knowledge to be groundless, dubious, distorted and misleading.

Looking at RKC's as integral parts of one or more arenas contributes to highlighting that their compositions, configurations and actions constantly and inevitably depend on their interactions with other social worlds. This awareness allows for due consideration of the role of mass media, for example, and, to an even greater extent, social media, the former mainly as a stage on which RKC's configure their relationships to other actors (see also Chap. 8 by Morsello et al. and Chap. 9 by Giardullo) and the latter as an opportunity to feed shared discourses and meanings including between subjects who may never physically meet (and this was particularly true during the pandemic). It is therefore clear that social media constitute, on one hand, a space of vital importance for RKC's, and, on the other, a context that conditions their actions and attitudes. At the same time, however, avoiding attributing to social media the capacity to determine the characteristics and lives of RKC's is thus easier. In short, RKC's are not victims of social media, although without them—and therefore without coming to terms with the rules by which they function—they would probably not exist.

Considering RKC's as parts of social arenas also provides us with an opportunity to pay due attention to the heterogeneity that characterises the networks constituting them. Within this heterogeneity, SWF recognises the role of non-humans, in the configurations of both social worlds and arenas, although such a recognition is not entirely convincing, as in ANT. In fact, although it has been stressed on several occasions that social

⁵ See also Chap. 4 by Bory in this book.

worlds and arenas are made up of human and non-human actors which mobilise discourse and share meanings (Casper, 1994; Clarke, 2005; Star, 1988, 2010; Star & Griesemer, 1989), non-humans still tend to be framed as ‘product[s] of the symbolic interaction[s]’ (Blumer, 1969, p. 10) of humans. Thus, whilst it is true that the SWF was ‘among the earliest in STS’ to focus on non-humans (Clarke & Star, 2008, p. 130), it did so as a theoretical perspective centred on *meaning-making* and is inclined to consider these as passive instruments dependent on human interactions.

In the case of RKC, however, the role played by non-human actors is anything but secondary and difficult to regard as passive. In three out of the four case studies examined in our research, this is extremely clear. Firstly, it is precisely non-humans which constitute the fulcrum of RKC’s discursive universes and mobilise their actions. Secondly, the central importance of non-humans is tangible even in RKC’s names. Look, for example, at the RKC based on opposition to the 5G network, i.e. a socio-technical infrastructure which comprises antennas, electromagnetic waves, data transmission standards, control and regulation systems and smartphones, to cite the most easily identifiable. Attributing a secondary role to this set of non-humans is difficult because they are the basis of the 5G network, enacting everyday discourses and, at the same time, they are identifiable as a dangerous enemy to mobilise against.

Viruses, vaccines, masks, respirators, health systems, lockdowns and other policy measures played a similarly strategic role in the configuration and evolution of the pro vaccine-choice RKC (see Chap. 8 by Morsello et al.). Not only did non-human actors such as these encourage the adoption of behaviours aimed at countering the spread of the virus or reducing its effects on people’s health, but they also contributed to labelling those who cast doubt on them—vaccine-hesitant and convinced anti-vaccine individuals—as irresponsible, ignorant, irrational and even dangerous.

In the case of the alkaline water RKC, the same can be said of mixers, sales networks, promotional events and a great deal more, without forgetting alkaline water itself, of course.

It is, perhaps, a little harder to identify the relevance of non-humans in the 5 Biological Laws RKC, but still not overly challenging. In fact,

recognising the role played by disease and trauma, i.e. any event that—in the view of 5BL RKC—disrupts individuals' lives and determines imbalances from which a state of malaise will later originate will suffice, namely artefacts such as the table graphically representing the 5 Biological Laws via which traumas are linked up with certain pathologies or by reconfiguring viruses as *friends of man*, i.e. as actors to come to terms with rather than as enemies to defend oneself against (see Chap. 7 by Crabu).

The importance of non-humans for RKC is thus very clear, and this makes it impossible to leave these in the background. Consequently, while SWF constitutes a theoretical basis for an epistemologically aware analysis of the processual character of knowledge (relationality) and its dependence on a specific point of view (positionality), and is thereby methodologically marked out by the principle of symmetry, what we need is to seek out an integration that allows us to better identify the agency of non-humans. In this respect, the great attention paid to non-humans by ANT (Callon, 1984; Callon & Latour, 1992; Latour, 2005; Law & Hassard, 1999) would suggest looking in this direction but this requires great caution. Simply borrowing a concept from one theory—in this case, that of non-human agency—and inserting it into another would not be correct, unless a sufficiently broad common ground between the two that would justify some form of integration can be found.

Fortunately, SWF and ANT seem to offer this possibility. As Clarke and Star (2008) have observed, we can, in fact, consider 'these two approaches as kindred in many ways (especially compared with earlier approaches to the study of science) and yet also as offering quite different affordances and accomplishing different analytical ends' (p. 122). Their not always overlapping premises notwithstanding, SWF and ANT adopt perspectives in which relationality, reciprocity, symmetry and positionality are of key importance, as we have seen. For ANT, in particular, not only is 'reality [...] a process' (Callon, 1986, p. 207), but actors are also inseparable from the networks of relationships to which they belong. Actors and networks are both intrinsically process-related in nature and there are thus only actor-networks. As Venturini (2019) has observed, in the actor-network expression, 'The hyphen stands for an equal: actor=network' (p. 8) and vice versa.

However, ANT struggles to recognise the relevance of meaning-making processes which, by contrast, occupy a prominent place within RKC. We can thus reiterate here what we have just discussed regarding non-humans but with the SWF-ANT roles reversed. The de-anthropomorphisation enacted by ANT to accord importance to non-human agency runs the risk of leaving the construction and attribution of meaning processes which are so important for humans in the background. Moreover, these are central aspects for RKC, which are communities built precisely on the sharing of universes of discourse which generate a sense of belonging and solidarity, often strengthened by the presence of common enemies.

A shared search for well-being is, in fact, a strategic element for the alkaline water RKC, and a specific interpretation of health and disease is a fundamental ingredient in the Pro Vax-Choice RKC, often in strong opposition to science and scientific medicine. The same is true, albeit with specific modalities and values, for the 5 Biological Laws RKC, which reconstructs an entire universe of discourse parallel to that of scientific medicine. The meaning-making processes at work in the case of the Stop-5G RKC appeal to concepts, theories and interpretations of reality, in a word to a mix of knowledge claims legitimised by arguments and practices with which its members identify. Here, too, the presence of a multifaceted enemy plays a key role, and it can take the form of science, corporations and, sometimes, hidden powers that are not always readily identifiable.

As has recently been underlined, however, ANT struggles ‘to engage with the history of the present and [the] latter’s constitutive role in understanding the experiences and actions of different actors’ (Prasad, 2022, p. 105). The *history of the present* means reconstructing the link between what is happening today and what happened in the past according to the logic of Foucaultian genealogy. An analysis of this kind allows for an interpretation of the different ways to understand the same claim by actors who have different genealogies and to comprehend, for example, how it is possible that during the pandemic, the hypothetically dangerous nature of masks—built on the basis of scientifically refused arguments—found support both among African/American communities and among white supremacist groups, as Prasad has shown.

Therefore, understanding RKC's without seriously considering meaning-making processes is extremely difficult, perhaps even impossible.

However, ANT cannot be said to completely ignore the meaning dimension attributed by human actors to their actions and their involvement in specific interaction networks. In some respects, it could be argued that meaning-making can be interpreted as a particular case of a more general category of processes to which those ANT calls *translations* also belong. Thus, for example, when the interests of an actor are translated in such a way as to make them compatible with those of another, when one convinces others that by becoming an *ally* of someone else, they are only pursuing their own objectives, and when actors share a *point of obligatory passage*, processes that can also be interpreted as meaning-making are still recognisable.

Clearly ANT is not interested in using such processes as explanatory resources and what matters is the relationships between the network's actants and certainly not the motives of the humans holding together the assemblages they form part of. We are, therefore, not arguing that meaning-making processes explain social phenomena. However, this does not imply that they do not play a role within them, for example, in triggering and developing translation processes. In other words, we can avoid reducing the complexity of the assemblages we intend to study by not applying outside theoretical categories and not assigning motivations, attitudes and beliefs to actants. Nevertheless, whilst this is true from the researcher's point of view, this does not mean that the same is true of human actants, for whom meaning-making processes remain important. Indeed, there is nothing accidental about the fact that a 'matter of concern' is, by definition, a matter for someone.

This may appear to be stretching ANT too far but it cannot be said to be incompatible with it, provided that including the attribution of meaning by human actors in the framework of translation processes remains one factor in the network-building process amongst many others and does not become a second-level explanation. ANT, in fact, aims to avoid surreptitiously introducing abstract conceptual constructions in the form of social factors, which would otherwise reduce the complexity of association processes rather than deploying their richness, as explaining elements (Latour, 2005).

A role for meaning-making processes can therefore be identified in ANT without contradicting it.

Taking into account what has been discussed thus far, we have attempted to integrate SWF and ANT as theoretical perspective with which to analyse RKC. Indeed, RKC fit the definition of social worlds as universes of discourse that give rise to collective actions perfectly, even if they are not necessarily based on consensus. SWF allows all these aspects to be considered within a consistent and organic theoretical framework. At the same time, there are a number of advantages to be gained from ANT in considering the highly significant aspects implicated in the processes through which the claims of RKC are built and legitimised: the relevance of non-humans to the social worlds in which refused knowledge is accepted and used, the fluidity of the configurations in which actants are involved and assembled, and as concerned networks acting both as emerging results of actants' interactions and as conditions for actants' existence. Therefore, our approach has adopted SWF as its main theoretical reference whilst supplementing it with relevant aspects from ANT, such as the constitutive relationships between actors/networks and non-human agency.

Cross-fertilising SWF with ANT allows us to consider both the social and technological conditions underlying RKC and thus grasp the ways in which scientific knowledge and science-based ordering processes are questioned by human–non-human assemblages. The aim is to explore how networking activities come into being, which social worlds enter arenas, how humans and non-humans are involved, how actors are enrolled in RKC, how parts of them can be reassembled to form new ones and how RKC can achieve temporary stability, shaping and sharing refused knowledge.

This creates the analytical conditions by which to demonstrate that not only do RKC shape and mobilise claims challenging the monopoly of science in defining reality but they also offer new meanings and options in everyday life and this was especially true during the pandemic, a period marked by deep uncertainty and collective disorientation.⁶

⁶See, for example, Prasad (2022).

2.4 Claim Legitimation Strategies

Considering the principles of relationality, reciprocity and symmetry, which play a core role in our approach to RKC, it can be observed that the knowledge legitimisation strategies their members resort to are similar to those of science in many respects. These strategies correspond to concepts already familiar to the STS field, although they are framed in various ways and their degree of stabilisation thus differs.

The first, and extremely general, strategy concerns *boundary work*.

As we have seen, every time we encounter refused knowledge and other types of non-scientific knowledge, it means that boundary work is under way and that true, accepted, prevailing knowledge is being established. As one of its earlier definitions set out, 'boundary-work occurs as people contend for, legitimate, or challenge the cognitive authority of science—and the credibility, prestige, power, and material resources that attend such a privileged position. Pragmatic demarcations of science from non-science are driven by a social interest in claiming, expanding, protecting, monopolizing, usurping, denying, or restricting the cognitive authority of science' (Gieryn, 1983).

Vice versa, as required by symmetry and relationality principles, RKC also engage in defining what is to be regarded as true knowledge and what, by contrast, is bad science or junk knowledge spread by interested groups (e.g. Big Pharma and institutional science serving the establishment) and a-critically supported by most people.

An extremely important aspect of boundary work is that it can be almost invisible, although it is sometimes easier to observe. When the latter is true, a public controversy is almost certainly under way in which many different actors debate a sociotechnical problem and discuss how to define and address it, thus configuring what have been called 'hybrid forums' (Callon et al., 2001). In fact RKC can be regarded as expressions of controversies which, for the most part, take place around boundaries demarcating *true* knowledge from *other* knowledge. Such controversies tend to remain latent for long periods and then resurface, sometimes aggressively, with an example being the discussions around vaccines during the pandemic.

As STS has demonstrated, parties to techno-scientific controversies attempt to legitimise their points of view by weakening those of their

opponents, seeking either to demonstrate the groundlessness of their claims or transforming these into elements supporting their own arguments (Callon et al., 2001; Collins & Pinch, 1979; Venturini, 2010). Therefore, attempts to enrol scientists as supporters of RKC claims are not infrequent, with an example being Nobel Prize winner Luc Montagnier, who supported the therapeutic properties of alkaline water and became a hero of the Pro Vax-Choice movement. Attempts to incorporate theories or experimental results accredited by science into the framework of elements in favour of RKC claims are also common. In addition to the famous Wakefield study on the supposed connection between vaccines and autism, which was initially published in *Nature* but then withdrawn, a further example is the highly casual use of quantum physics by supporters of the 5 Biological Laws and of widely accepted scientific concepts, such as electromagnetic fields by the Stop-5G RKC.

Combining a range of elements to develop a convincing argument corresponds to a second strategy that can be described as *syncretism*. This legitimisation process comes into play when RKC members assemble activities, ways of doing things, styles of thinking, discourses and individual statements which come from different domains but are combined into a new configuration. Examples of syncretism can be found on both the science side—such as the inclusion of acupuncture in Western scientific medicine—and RKC side, with an example being ‘family constellations’ as part of the 5 Biological Laws.⁷

Syncretism is not a mere juxtaposition of heterogeneous elements. It is a patchwork with a shared discursive framework, new mixes which come across as meaningful and coherent to RKC members (see Chap. 6 by Picardi et al.). Therefore RKC members, like science, act as *heterogeneous engineers* (Law, 1987) committed to maintaining their claims through constant assembling of elements that are usually treated as belonging to different classes—human and non-human, scientific and non-scientific, individual and collective—and arguments otherwise belonging to different domains and delivered by various communication channels (scientific journals, blogs, social media, traditional media, laws and regulations and

⁷ Family constellation therapy is a type of psychological counselling based on the idea that problems can filter down through generations to cause stress in the present moment.

informal exchanges in the most diverse contexts, from scientific conferences to training meetings, assemblies to street protests).

If we then focus on the eminently discursive level, syncretism strategy can be viewed as a combination of contents, concepts and discourses from different narratives with a view to building a new narrative, which can also be more or less organic (see Chap. 5 by Tosoni).⁸ This is akin to what happens with a musical mash-up and many other forms of cultural hybridisation.

It is worth noting that one of the main components of the syncretism practiced by RKC's in support of their knowledge claims is *personal experience*. This is a validation criterion that is mentioned recurrently with regard to personal experiences of disease, for example. Full-blown personal experiences are not always required, and others having had such experience is sometimes enough, i.e. with the same disease or belonging to the same entourage as parents, friends and colleagues.

This epistemological resource based on personal experience is thus a crucial aspect supporting refused knowledge. Anything proving useful in dealing with a situation can be considered proof of RKC's knowledge claims, both by making it meaningful and by suggesting the most appropriate way to deal with it. The great value accorded to experience—fully personal or even just shared—thus assigns a prominent role to individual testimony within the refused knowledge legitimisation process. In fact personal experience as a criterion for judgement and validation seems to have acquired increasing importance in our cultural context, especially when people are faced with health problems of various degrees of severity (Brewer et al., 2017; Dubé et al., 2013; Kata, 2010; van Zoonen, 2012). Examples of this are tumours diagnosed, deciding whether to vaccinate one's children or clinically unexplained symptoms that might be interpreted as effects of exposure to electromagnetic fields. However, in these and many other highly emotionally charged cases potentially also comprising a biographical break, establishing whether the knowledge of scientific experts is significantly more reliable than direct experiential

⁸ However, we should not forget that the concept of syncretism is necessarily based on what has been called the 'bias of purity' (Law et al., 2013, p. 174) as it assumes that there are categories by which our reality can be organised unambiguously, forgetting that these categories are derived from constant *purification* efforts (Latour, 1993).

knowledge or the knowledge of people within one's own social world can be difficult. Therefore, intimate coexistence with what is framed as *a problem I have direct experience of* (e.g. when I vaccinated my son he had a terrible allergic reaction) makes it difficult to rely on the skills of a doctor which, whilst certainly based on scientific evidence, are, precisely for this reason, aseptic and therefore those of someone who has not experienced this same problem *first hand*.

The experiential knowledge shared within RKC's is, in fact, configured as a form of *knowing otherwise*, in which the direct and/or shared experience dimension is both a legitimisation criterion and an action resource. For these same reasons, RKC's recognise authority based on *experiential expertise*, i.e. the expertise of those who are close to people in a RKC who have had similar experiences or who have met many people in the same condition. This authority is further strengthened when practicable solutions without too many techno-scientific mediations are offered, as these are more readily understandable and thus reassuring. Indeed, within the logic of experience-based legitimisation strategies, expertise based on institutional credentials (education, academic position and publications) is considered distant, abstract and useless, even harmful. The traditional expertise-building process is therefore turned on its head. Rather than expertise being an institutional credential enabling experience to be acquired, it is experience that certifies expertise (Heyen, 2020; Merkley, 2020; Vuolanto et al., 2020).

In some ways, the social worlds of self-help groups—from alcoholics anonymous to patient associations—move precisely in this direction. However, in the case of RKC's, knowledge based on personal experience implies a watershed with scientific epistemology to the extent that only limited space is left to scientific knowledge, the opposite of what happens in the case of patient associations and groups (Epstein, 1996; Rabeharisoa & Callon, 2002).

However, RKC's do not reject science totally or definitively. Rather they combine validation criteria based on experience with syncretism by selecting and inserting scientific knowledge—or portions of it—into the framework of their shared knowledge to generate something resembling a consistent whole. RKC's are thus making instrumental use of scientific knowledge.

This reconfiguration of scientific knowledge not infrequently pertains to a further legitimisation strategy that seeks, in the sense of ANT, to translate the forms and methods of scientific research into RKC's discourse and practices. It is a matter not only of importing scientific knowledge into a new context but also of enhancing the credibility of this context by emulating official scientific practices. This is a strategy that can be described as *mimicry*, with consolidated scientific practices emulated in a functional way to confer credibility on refused knowledge.

This happens when RKC's use symbols, procedures and repertoires typical of scientific language to produce facts and evidence to support their claims. It is a strategy that has already been documented, for example, in the creationism-evolutionism debate (Park, 2001) or in the case of conspiracy theorists, who 'flaunt with academic credentials (professor, Dr, MD, etc.), publish books with scholarly sounding titles and adopt a style of writing that mimics mainstream academia [... so that they] make a parody out of science [... thus becoming] the pathological Other of modern science' (Harambam, 2020, pp. 13–14). This strategy also encompasses attempts to enrol scientific experts as supporters of refused knowledge or those with the scientific credentials which come with working, currently or in the past, in universities or research centres, perhaps in marginal positions, or even simply as graduates.

It should also be underlined that emulating scientific practices tends to take an idealised version of science as its reference point, portraying it as free of interests, exclusively devoted to the good of humanity and designed to achieve objective knowledge (Harambam, 2020; Jaspal et al., 2012; Prasad, 2022). At the same time, mimicry can concern the borrowing of scientific formats, such as the organisation of a training course in a typically academic style.

2.5 Conclusions: Why Should We Take RKC's Seriously?

One of the most interesting results which emerged from our research is that the strategies adopted by RKC's to support their claims are also clearly recognisable in the processes by which scientific knowledge is

constructed and legitimised. Is science not continually engaged in defining and maintaining boundaries? Think, for example, of those which separate it from heterodox cognitive practices or those which distinguish between disciplines, schools of thought and theories or paradigms. Is not the formulation of new concepts, research programmes and tools often derived from the hybridisation of different research fields, from their combination into a new organic framework of elements previously belonging to separate fields? Does not the history of science very frequently seem to proceed through processes of syncretism? Furthermore, could not research work in *normal science* à la Kuhn be interpreted in many ways as an effort to remain consistent with the dominant paradigm, even through mechanisms of mimesis?

From this point of view, refused knowledge legitimisation strategies truly resemble those adopted by institutionally accepted knowledge. After all, is this not one of the main acquisitions of STS? Is it not this similarity that underlies the principle of symmetry? Certainly, identifying differences, even remarkable ones, is by no means difficult. Such differences seem, above all, to concern differing interpretations of the expression *knowledge based on experience*. For RKC, what stands out is the reference to individual experience, the validation derived from subjective feelings and having *experienced something in the flesh*. Whilst such knowledge can then be strengthened by sharing it with others whose experiences are similar, the individual subject still remains the starting point in the cognitive process and the benchmark it returns to, to stabilise its outcomes.

As we know, scientific research also relies heavily on experimental practices, i.e. methods of legitimising knowledge based on experience. However, it is an experience built and implemented by reference to collective parameters that are programmatically defined for the purposes of going beyond the individual, despite the diversity of the epistemic cultures to which reference is made (Knorr-Cetina, 1999).

However, if this specific kind of reference to experience is science's determinant strength, it is precisely this specificity that makes it unattractive to many, especially in the face of difficult situations such as illness, uncertainty and loneliness. Scientific knowledge can thus appear aseptic, detached from subjective feelings and distant from people's living

experiences which are vivid precisely because they feel unmediated and thus open to personal interpretation.

It is exactly this distance from the everyday life sphere—which has grown over time, partly thanks to the development in science of languages and practices which feel increasingly esoteric for lay people—which gives RKC space and sparks their interest. However, all this makes RKC all the more significant to our understanding of the social processes in which we are embedded, rather than considering them as exotic objects pertaining to a tiny minority and thus to be studied with the curiosity of arrogance.

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3

Embracing Refused Knowledge: The Turning Processes

Paolo Volonté 

3.1 Introduction

Endorsing and adhering to a body of refused knowledge is a significant event in an individual's life trajectory. While apparently merely a cognitive act, it is really much more than this. Refused knowledge typically engenders communities of concerned people engaged in a contentious relationship with science, which is the protagonist of rejection and, therefore, of the act qualifying a specific body of knowledge as 'refused'. Thus, embracing refused knowledge often implies joining a social world (Clarke & Star, 2008), developing interpersonal bonds, entering networks populated by human and non-human actors and cultivating institutionalised social relationships which go beyond mere instrumental objectives and shape a feeling of belonging.

Hence, taking part in a social world characterised by refused knowledge is often the outcome of a significant personal turn. Rather than

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ascribed it is acquired through a biographical transition. The biographical trajectories of people endorsing refused knowledge of any kind frequently reveal a gradual shift away from an original state of alignment with an institutional knowledge system—that is, a system of beliefs legitimised and promoted by certain epistemic institutions in society, such as science, the educational system and medical authorities—to alternative ones refused by such institutions and shared by a minority community. This applies to the four communities considered here: Pro-vaccine choice, Five Biological Laws (5BLs), Alkaline Water and Stop 5G. Embracing refused knowledge usually implies an important change in people's lives. Joining a refused knowledge social world is a challenging development in an individual's personal biography involving various kinds of costs—for example, in work and social relationships, political choices, health choices, body care practices, etc. Bridges with certain friends and relatives may be burnt, new political engagement with a niche party or movement may reshape life interests and time allocation regimes, and refusing science-based medical advice may lead to long periods of illness and an ongoing struggle against public welfare health systems. Such personal transitions are not merely cognitive in nature, then, but also emotional, behavioural, social and material.

Moreover, analysing the processes leading people to turn to refused knowledge is not simply of use in producing a thorough description of refused knowledge social worlds; it also increases our understanding of the dynamics of knowledge construction and stabilisation in general, including scientific knowledge (see Chap. 2, by Federico Neresini). Adopting a symmetrical standpoint, the decision to believe in a body of knowledge—be it socially institutionalised or alternative—is epistemically neutral, meaning that the choice cannot be explained simply on the basis of the greater or lesser truthfulness or objectivity of the knowledge itself. Hence, a shift from institutionally legitimised knowledge to refused knowledge is a topical moment in which the non-epistemic mechanisms leading to the choice may also emerge. What makes people change their minds and turn to refused knowledge? What makes them form an opinion and embrace scientific knowledge? These two questions address the same social knowledge stabilisation dynamics.

In this respect, whereas at first glance epistemic neutrality can make such turns seem gratuitous and, therefore, of little interest in understanding the construction and stabilisation of knowledge, in actual fact the opposite is true, because it is precisely in turning processes that the forces contributing to stabilising bodies of knowledge exert their power. Moreover, where embracing *refused* knowledge is concerned, with its implicit turning from one knowledge system to another *competing* knowledge system, the forces governing adherence to a knowledge system become more evident. In fact, in such cases, turns involve an at least partial estrangement from prevailing beliefs, as they involve a decision not to recognise the legitimising power of science—a social institution benefitting from widespread recognition in contemporary societies. Such turns involve weighty choices that can be explained only in relation to particularly stringent (non-epistemic) mechanisms.

Thus, the subject of this chapter is not communities as such, with all their characteristics and peculiarities, but the experience of transition from one social world to another—that is, from a social world governed by scientific institutions to a social world constantly struggling against rejection, and often, stigma, from science-based people and communities. Studying such transitions is a tool by which to enquire not only into adherence to refused knowledge but also into the socio-material dynamics generally at work in the processes of construction and stabilisation of knowledge, even when knowledge is legitimised by scientific communities.

3.2 Turning as a Process

This chapter enquires into the transition to refused knowledge as it occurs in the four social worlds examined in this book. Refused knowledge social worlds are often based on ties of various degrees of closeness, routine interactions and institutionalised organisations (Clarke & Star, 2008, p. 116). Such refused knowledge communities (RKC) defend ‘visions of science and medicine that are denied acceptance or even consideration by institutional science’ (Bory et al., 2023; see also Picardi & Agodi, 2021). They function as actor-networks of heterogeneous socio-material

resources and agents engaged in efforts to negotiate and resist prevailing scientific discourses and produce knowledge offering new meanings and options for addressing everyday life to members. In the four cases considered here, the form of this framework varies, as the introduction of this volume highlights.

However, since this chapter is not concerned with RKC internal dynamics, but rather with the turning processes that lead individual agents to embrace refused knowledge, its perspective is a different one. Although the four social worlds considered are characterised by existing socio-material actor-networks, we will see here that these do not play a decisive role in turning processes. Turning implies enrolment (Latour, 2005, p. 28) in a new social world, but this is more frequently a matter of a slow progression within a life trajectory in which RKC are minor players. Anticipating some of the results of this analysis, I will note here that turn is usually based on a pre-existing affinity; triggered by an event that is not necessarily related to a specific actor-network, although it can become such when it is experienced and defined by the individual as a 'problem'; supported by human micro-networks of strong ties generating affiliation—rather than by membership in wider communities; and reinforced precisely by subjects (agents of science) interested in preventing new members joining RKCs. In other words, the turning process highlights a key principle of Actor-Network Theory, namely that actor-networks (in this case, communities) are assemblages in unstable equilibrium, fleeting stages in a constantly evolving process—not groups but stages of group formation (Latour, 2005, pp. 27–42). Embracing refused knowledge is not the same as becoming part of a stable RKC.

Moreover, we will see that the turning process is often inherently powerful for those involved, meaning that from the human actor perspective it is perceived as natural and necessary. It is a kind of moral career (Goffman, 1959) in which the affiliation to a micro social group activates one's own 'affinity' to refused knowledge and enables individuals to 'become willing' to be part of the relevant social world (Matza, [1969] 2010, pp. 111–112). Those 'converting' to refused knowledge are not passively enrolled in existing actor-networks. Indeed, they experience *conversion*, not *contagion* or *infection* (Matza, [1969] 2010, p. 102).

In the remainder of this chapter, I will return to the singular aspects of this rather brief outline to show the form the turning process takes in the lived experiences of certain individuals who have embraced refused knowledge. This is based on a set of 67 in-depth interviews conducted during this research, in accordance with the narrative interview method—partially face-to-face and partially online (due to pandemic-related limitations)—and analysed with the support of qualitative data analysis software, although only a small proportion of these will be explicitly discussed here. The interviewees included both experts engaged in legitimising and disseminating refused knowledge and laypeople belonging to the respective social worlds.

3.3 Conversion Does Not Equate to Awakening

In various realms of social life, conversion to alternative bodies of knowledge has often been described as a form of awakening. Similar to religious conversion—in which revelation is often experienced as a life-changing event leading to redemption and interpreted by means of a metaphor comparing it to ‘waking up’ after a long sleep—in numerous other social fields conversion to a new system of beliefs is described by protagonists with an ‘awakening’ narrative (DeGloma, 2010; Harambam, 2020, pp. 134–137).

The same narrative is to be found in our RKC. Here, the awakening metaphor is more frequently applied to others than to oneself, i.e. to those who are considered to be still asleep. For example, Ester, a pro-vaccine choice supporter, hopes

that people wake up, they begin to find out more, not to be afraid, because fear blocks you. (Ester/Pro VC)

This leverages a first idea of awakening—that is, the end of a lethargic state, a transition from torpidity to activity. Others adopt a more cognitive idea of awakening that is often linked to the concept of

enlightenment, to an image of transition from darkness to light. Luigi is a Stop 5G movement activist. He describes the tough lives of those suffering from electro-hyper-sensitivity (EHS), i.e. experiencing physical discomfort in the presence of electromagnetic fields:

You experience abandonment, not being believed, you see this pressing technological progress all around but the people alongside you do not believe you (this is a big problem), and there are no answers from the institutions. It is a very marked condition of isolation. (Luigi/Stop 5G)

In this state of solitude, electro-hyper-sensitive people experience darkness, a situation in which they feel something that nobody else can see. Therefore, meeting people who share their experiences is seen as a sort of enlightenment, as light at the end of a tunnel. For example, describing the origins of the Italian association of EHS sufferers (Associazione Italiana Elettrosensibili, AIE), which is a striking case of biosolidarity (Bradley, 2021, pp. 543–546), Luigi added:

I find other people like me, and *I see the light*. I say to myself: ‘wow, I’m not alone’. (Luigi/Stop 5G, my emphasis)

Although the awakening metaphor gets across the idea of radical change very well, it also provides a misleading impression of *sudden* change. It is an ambiguous metaphor suggesting a clear turnaround in several contexts: the bodily awakening that occurs at the end of a period of lethargy—that is, a transition from torpidity to activity as it is used in the political awakening context; mental enlightenment and the end of drowsiness as implied by the cognitive awakening framework, in which being awake means being aware; the end of a dreamlike state—that is, the transition from illusion to (alleged) reality, as implied in the ideological or religious awakening framework.

However, the turn to refused knowledge is rarely a sudden change. On the contrary, it is usually the gradual deepening of an attitude that the protagonists feel is congenial as it ‘resonates’ well with their values and habits. As Thomas DeGloma observed, awakening stories are often not personal experiences but cultural patterns adopted by individuals to make

sense of their experiences. He claims that ‘different communities have their own *foundational awakening stories* that although not all purely autobiographical, provide story templates and cultural tools that individuals use to construct their personal awakening accounts’ (DeGloma, 2010, p. 522, see also Chap. 7 of this book by Crabu). Accordingly, I would argue that when interviewees use awakening images for the changes taking place in their lives, they are employing a cultural resource of use in making sense of what happened, which, however, conceals the lengthy underlying journey towards adhesion to refused knowledge. For example, Piera—an anti-gymnastics teacher and 5BLs follower—recounted:

Homeopathy came via friendships, as I hadn’t solved my problems and maybe the [medical] approach did not resonate with me. In my case, at the beginning there was a hormonal problem, so, you know, they send you to the endocrinologist, who starts giving you pills. I felt that such pills might be fine, rationally they help, but they upset me. [...] Approaching homeopathy—by the way, the homeopathy of an anthroposophical doctor, hence based on that kind of research—led me to reconsider everything a bit. Anti-gymnastics arrived in high school via the gymnastics teacher who was a fairly alternative teacher and lent us a book. [...] Through anti-gymnastic work we feel what is good for us step by step through our bodies. [...] For me the 5BLs have also meant this: deepening the biological meaning of what the body expresses even more. (Piera/5BL)

Piera’s movement towards the 5BLs—originating from a physical condition to which traditional medicine provided unsatisfactory answers—was gradual and passed through various alternative approaches to health (homeopathy, anti-gymnastics, Steiner’s medicine) in a crescendo of radicalism and distance from science. This gradual transition from compliance with science to adhesion to refused knowledge is a common feature of interviewees’ stories and confirms earlier research results (Rogers & Pilgrim, 1994). The following excerpt is paradigmatic. Franco is a hospital nurse and a 5BLs expert proactive in promoting this approach on the web. He told us:

The problem is that in ‘93–‘94 I got sick with depression [...] and I did not know what to do, as conventional drugs kept me sedated but certainly not

happy. One day, as I knew a doctor in my hospital who practiced acupuncture, an anaesthetist [...], I got curious. I wanted to see if I could find a way out through acupuncture. It wasn't really acupuncture [that helped me], it was a decoction of Chinese herbs. After four days of therapy, I was fine, I was really fine. [...] So, I got curious, I started studying and I studied Chinese medicine for ten years. I also got a Chinese massage degree since, as a nurse, I am not allowed to do acupuncture, much less Chinese pharmacology. Later, [...] I began to be interested in other visions: Ayurvedic; then I read some orthomolecular books, I became interested in herbal medicine, until one day in a summer bookshop here in our area, I found a book by Claudia Rainville [...] on the psycho-somatic meaning of symptoms. [...] In this book I found a reference to Dr Hamer: 'Who the hell is he?' [I asked myself]. [...] I went to read some news online about Dr Hamer, I began to grasp the meaning of what he was trying to disseminate and, oh well, I realised that this was the answer. In the sense that Chinese medicine gave me many answers, but it did not give me the ultimate answer, which is [the answer to the question]: 'Why is this happening to me? Why me?' (Franco/5BL)

This narrative touches on several elements which show up very frequently in the personal stories of those embracing refused knowledge. They testify to complex trajectories in which circumstantial events act as triggers for choices coming from afar and taking root in people. Like Piera's story, Franco's account starts with 'a problem' (depression). Such transitions often originate from problems (usually health related) that people encounter in their lives. As Michael Bury has argued, health problems often elicit more profound biographical disruptions involving 'a fundamental re-thinking of the person's biography and self-concept' (Bury, 1982, p. 169). An event presents as 'a problem' not only because it constitutes a nuisance or a danger but also to the extent that conventional medicine cannot find a quick and effective response to it. Otherwise, it would not be a problem. Those involved thus start taking note of those recommending alternative remedies—in this case, acupuncture. The interest in remedies that are alternative to allopathic medicine leads to individuals meeting other people belonging to social worlds in which criticism of conventional medicine is widespread and shared and in which information on alternative medicines is promoted and facilitated. Thus,

in a crescendo, individuals encounter new bodies of knowledge rejected by Western science increasingly radically (in this case, Chinese, Ayurvedic, orthomolecular and herbal medicine, and then the 5BLs).

Awareness of the progressive nature of embracing refused knowledge allows us to avoid the simplistic juxtaposition of science and pseudoscience, scientific and anti-scientific approaches to problems. Amit Prasad (2022) recently suggested that investigating anti-science claims requires examining not only what these claims affirm but also how they are discursively framed and circulated, as it is only then that we discover that such claims are only rarely truly anti-scientific and generally critical of 'certain institutional relationships of science' (Prasad, 2022, p. 90). I maintain that the lengthy and complex processes involved in embracing refused knowledge confirm this thesis, as they imply constant negotiation with science. Membership of a particular refused knowledge social world is not definitive and, neither, frequently, is it complete. The individual life stories show that, for laypeople in particular, adherence to a body of refused knowledge is often simply a transitory stage towards another and different body of refused knowledge better resonating with individual values and expectations: one might believe in the vaccination-autism link as an intermediate step along a path leading to the endorsement of New Germanic Medicine which, in turn, may be an intermediate step on the way to South American shamanism.

Moreover, individuals' adherence to refused knowledge is subject to change and second thoughts and often only partial, in the sense that it does not necessarily imply a willingness to believe all the theoretical statements or definitions of the facts encompassed by a certain body of knowledge. Quite the opposite, many interviewees place very clear boundaries around the field of knowledge worthy of belief, excluding not only knowledge accepted by science but also opposing arguments. Olga, a pro-vaccine choice mother and graduate, argued:

Taking sides [in the vaccine quarrel] is exhausting; you need a clear understanding of who people are, their reasons. I feel I have distanced myself from both sides. I don't like the extremism of some people who are critical of vaccinations because I feel that though they do [a lot of] sharing, sharing is a very easy task, all you have to do is click, you just read a few lines and...

Over the years some [of them] have labelled people like me—who actually feel extremely moderate—as irresponsible. They have exposed themselves to several legitimate criticisms. I have heard people use arguments that are truly bordering on science fiction, where somebody who knows just a little more than you can make you look like an idiot. (Olga/Pro VC)

Several other interviewees showed a similarly cautious approach. Angelo, an expert on, and professional promoter of, alkaline water producing devices, said:

I'm saying a very important thing, and it should be emphasised: we are not talking about water that cures, heals or prevents or anything like that. As they taught us, you need to have a healthy diet, drink healthy water. And then it's our own body which heals. [...] This is a necessary aside, because unfortunately there are all sorts of things on the web. Just think, there are even people who say that water heals tumours and the like. [...] Well, it's not part of my ethics and individuality. (Angelo/AW)

Hence, joining a refused knowledge social world is often combined with rejecting certain parts of that body of knowledge and social world. As Olga repeatedly stated, defending a refused knowledge argument is a challenge and not just because it is rejected by science and mainstream communities. Adhering to refused knowledge implies constant renegotiation of one's position in the world.

For the reasons examined here, the metaphor of sudden conversion after a revelation, spiritual enlightenment, awakening is not particularly useful in understanding the process of embracing refused knowledge. It is certainly an element in RKC's founding narratives (see Chap. 4 by Paolo Bory), but this fact regards the birth of such communities rather than individual adherence to them. It is also widespread among academics criticising what they see as pseudo-scientific theories (as shown by Harambam, 2020, pp. 182–187), but this is just a clear case of scientific 'boundary work' (Gieryn, 1983): it says a great deal more about the science which rejects certain bodies of knowledge than the social worlds accepting them.

I will thus now cast aside the religious tropes and examine the transition process, attempting to identify its main drivers.

3.4 Transition Drivers

As observed above, certain disruptive biographical events appear to act as triggers for the turn to refused knowledge. Yet the outbreak of a ‘problem’ is usually a trigger, not a driver in the turn. It is the circumstance that causes a number of pre-existing factors to develop and associate into a new assembly that becomes remarkably significant in an individual’s life.

Certain refused knowledge claim-makers (see Chap. 7 by Stefano Crabu) have a clear understanding of the contingent nature of ‘problems’ and, simultaneously, their relevance in triggering a possible turn. Indeed, they leverage these to acquaint potential newcomers with their new insights—that is, to enrol them into the alternative social world. They act as spokespersons of the new association (Latour, 1987, pp. 70–74). This is the case of Giovanni, an expert and trainer in the field of alkaline water, who himself turned to holistic medicine and salutogenesis (see Mittelmark et al., 2017) following a significant ‘event’ in his life—that is, his father’s death from a stroke. Speaking of typical clients, he said

My typical client was someone who had already bounced between one specialist and another without finding a solution to her problem. So, my protocol is mainly about identifying the cause. Then I use investigation tools to figure out what’s wrong. Most of the time it all starts from the intestine. [...] The person who turns to me most is somebody who has a problem and cannot solve it. So, what’s my job? *It is to bring out the problem*. So, I suggest some tests, which can be a test for evaluating any gut dysbiosis. (Giovanni/AW, my emphasis)

Giovanni leverages a possible problem by ‘bringing it out’, which implies two aspects simultaneously: making a problem visible and turning it into ‘the problem’. By making certain intestinal pH alterations visible via measurements and data, Giovanni brings out what appears to be the ‘real’ problem that the client was unable to solve and pushes him or

her towards an effective solution by means of a diet that includes drinking alkaline water, thereby enrolling the client in the respective social world.

This story also highlights that the original problem prompting the client to contact Giovanni had become a problem because conventional medicine had not been able to solve it and led to the client trying a range of specialists without success. The enrolment in the new association was facilitated by an *interessement* elicited by science itself, which therefore actively contributed to the transition to refused knowledge. This is one of a number of factors that occasionally become agents in the *interessement* and enrolment (Callon, 1986) of individuals in a refused knowledge social world. I will examine the most relevant factors below.

3.4.1 Tests, Treatments and Protocols

In many of the stories told by refused knowledge followers, illnesses and diseases become ‘problems’ when medicine turns out to be incapable of producing the expected response. For our interviewees, this is mainly due to the following three factors.

Firstly, and most obviously, medicine is seen as incapable of solving patients’ problems when it fails to give *quick* and *certain* answers. As Piera and Franco’s accounts above testify, interviewees very frequently describe the origin of their ‘problem’ as the outcome of an attempt to treat a disease through medicine, which turned into an exhausting sequence of visits, tests, uncertain and delayed diagnoses and therapies replete with side effects. When diagnostic tests and medical treatments do not work, when they go ‘on strike’ (Latour, 1988, p. 298), the whole conventional medicine framework begins to run out of steam.

Secondly, medicine’s hyper-specialisation is at fault because it pushes doctors to focus on the disease, or even the symptoms, rather than take care of the patient and heal the body. Protocols are the main actants in this approach to illness. Experts who embrace refused knowledge, especially medical professionals, often see protocols as the main flaw in the conventional approach to illness, as the following excerpt makes clear (see also Chap. 7 by Stefano Crabu):

I am absolutely against certain protocols because I maintain that they are not applicable to everyone. That is, I am for medicine based on a person's needs. I mean, a guideline is fine, a protocol is fine, but then the protocol must be applied specifically to that person, it must be contextualised to what we are doing. (Iacopo/AW)

Thirdly, medicine lacks empathy. Patients are not listened to and emotional support is not given. This accusation is levelled against medicine by many interviewees, but it is especially evident in the case of electro-hypersensitivity sufferers. This condition—which emerged from our study of the Stop 5G social world—is not recognised by the World Health Organisation (WHO), which considers it a syndrome of psychological origin arising from a nocebo effect: if you see an antenna and feel sick, it is because you are somatising your fear of electromagnetic fields. This is the 'tragedy' experienced by electrosensitive people, as Luigi—the president of the Italian association of EHS sufferers (AIE)—emphasises: 'By not recognising EHS, WHO effectively prevents national health systems from carrying out adequate diagnostic, prognostic and therapeutic processes. There is a segment of the population totally abandoned, which partially—in one way or another—joins us' (Luigi/Stop 5G). The 'state of abandonment' in which health systems leave patients suffering from symptoms that they attribute to electromagnetic fields pushes them to turn to those who listen to them and take their concerns seriously, that is, to institutional subjects of refused knowledge social world, such as AIE.

3.4.2 Social Relationships and Family Background

Thus, it is no surprise that joining an RKC generates a magnetic field which reinforces individuals' interest in, and adherence to, that body of refused knowledge. The above 'state of abandonment' drives people into the arms of AIE, which not only provides emotional support but also urges them to take an interest in the refused knowledge itself.

Yet individual actors may play a key role here as the network's spokespersons, to an even greater extent than communities and groups. Frequently, such individuals act as guides or life teachers prompting

individuals to venture into the refused knowledge *terra incognita*. They are often friends, as in the case of Beatrice, an independent 5BLs populariser, who told us:

At forty I was really a disaster: always sick. After a trip to India, I had furunculosis for four years. And there, in fact, some friends told me: 'Look, try to make some changes. Watch your diet!' Until I was forty I had never linked up diet and state of health, therefore, all of a sudden—this friend was a raw food vegan—[...], the transition to raw was incredible: in a week I felt like I had never been so well. (Beatrice/5BL)

In some cases, these actors are charismatic claim-makers—that is, experts recognised by a community of followers who acknowledge their right to set the correct interpretation of a given situation. An interesting case of this type is Thérèse Bertherat (see Bertherat & Bernstein, 1980), a French physiotherapist who invented anti-gymnastics and steered Piera to the discovery of the 5BLs community. As a charismatic figure, Thérèse was a point of reference for her community of followers, in terms of values and norms. When Piera was faced with an emergency—a severe pain in her shoulder that Arnica could not treat at a time in which she was unable to contact her homeopath—she turned to a friend who was also an anti-gymnastics teacher and this friend told her, 'Thérèse would tell you: don't remain in pain. Because pain isn't good for you, it doesn't allow you to be clear headed. [...] I'm sure Thérèse would tell you to take a painkiller' (Piera/5BL). As an actant, the figure of Thérèse exerted influence on her followers even in her absence, as an 'entity that does not sleep' supporting 'associations that don't break down' (Latour, 2005, p. 70).

In many cases, the part played by the environment of origin is an important one via the influence of parents, other family members or friends, who prepare the way for the growth of interest in refused knowledge. For example, Carla, a 5BLs follower, talked of a sister interested in 'mystical things' who, like her mother, became a Buddhist. Her sister was the intermediary who introduced her to Hamer's theory and to a number of New Germanic Medicine experts as well. Similarly, Nunzia, a pro-vaccine supporter whose father abandoned a family of four children,

grew up in the care of a wealthy aunt who was extremely interested in ‘natural nutrition, shiatsu, meditation, all these things’ (Nunzia/Pro VC).

3.4.3 Education

Education is a notoriously important driver in the dissemination of knowledge refused by science, not because adherence to refused knowledge is fostered by scientific illiteracy but, quite the contrary, because it correlates with a high educational level (McCright & Dunlap, 2011; Veldwijk et al., 2015; Yang et al., 2016). This is confirmed by our research, though within the limits of a qualitative approach. Having interviewed several highly educated subjects, the role played by higher education in the process of embracing refused knowledge becomes visible, especially in relation to medical or nursing education, which several of the interviewees had. The knowledge of these latter on human physiology, chemical reactions, various medical doctrines, physiotherapy practices and so on is a resource that experts as well as laypeople can easily draw on to justify their adherence to refused knowledge. We have already met Franco and Iacopo, who base their refused knowledge expertise on their previous nursing and medical education.

Yet, formal qualification is not the only way of acquiring knowledge strong enough to support resistance against scientific rejection. Several members of these social worlds with varied educational backgrounds have, over the course of time, developed wide-ranging competence in medical or physiological matters to strengthen their adhesion to refused knowledge. Thus, their biographical turns are rarely based on blind faith and pure trust in individuals or institutions. More often, they are founded on arguments rich in technical data and specific information that is occasionally syncretistically derived from fragments of specialised training and otherwise from self-education and constant net surfing.

3.4.4 The Media

Obviously, media is a fundamental driver in such transitions, particularly since, for many, the internet is their primary source of information in the process of *interesement* for refused knowledge. Yet, it does not work as a guide. In Chap. 5, Simone Tosoni argues that the ‘university of Facebook’—as an interviewee (Nunzia/Pro VC) calls the immense wealth of information stored on the internet or actively available through social networks—must be understood as primarily a narrative ecosystem (see also Innocenti & Pescatore, 2017). This means that the internet works as a repository of news, discourses, arguments, symbols and everyday events that can be appropriated to interact in a specific social world, such as an RKC, or to justify non-conformist choices to those who either do not share them or oppose them. Accordingly, in the turning processes, the media system complements social relationship networks and extends and supplements the information circulating offline. A turn to refused knowledge mainly or exclusively based on media information is not a pattern. Obviously, the media system also offers newcomers a space of interaction in which enrolment can be activated, practiced and made known.

3.4.5 Personal Dispositions

Pre-existing factors also include personal dispositions, specific attitudes, even the reprocessing of experiences dating back to childhood or family relationships, as the following excerpt makes clear:

My mom had a difficult delivery. [...] So I was born with a broken collarbone, and my mother really suffered and was always telling me ‘They stitched me up to the rectum’. In short, I didn’t understand that the problem was me being big, because I was born weighing 4.2 kilos. [...] Then you blame yourself a bit: I was big, so, you know, it hurt her. (Nunzia/Pro VC)

Nunzia resorted to this narrative, which evokes a powerful emotional charge in her relationship with her mother, to make sense of her ‘problem’: a miscarriage followed by a curettage that she refused to have done.

The bridge she built between the accounts of her own birth and her decision to refuse medical aid after her miscarriage is revealing of a disposition against surgical intervention in a context related to giving birth. Clearly, the origins of this disposition date back to previous experiences that escape sociological observation.

Other interviewees occasionally resorted to conspiracy theories, which however appeared to be a general framework designed to make sense of the world rather than a specific interpretation of their ‘problem’. Such a framework is then activated in the turning process and applied, for example, to firms considered to be at fault for pursuing their economic interests rather than meeting the real needs of sick people: pharmaceutical companies, grouped under the Big Pharma umbrella concept, or communication companies, especially in the case of the Stop 5G community.

3.5 The Turning Process Is Not Driven by an Anti-scientific Stance

Just as the awakening metaphor is not an appropriate way to describe the turn to refused knowledge, interpreting individuals’ refusal of science by means of categories such as anti-scientific attitude, irrationalism, spiritualism and esoterism is equally inappropriate. The dominant attitude within refused knowledge social worlds is characterised by a marked rationalism, in accordance with the standards of Western science. As Michael Lynch has argued, contrasting ‘objective facts’ and ‘appeals to emotion and personal belief’ fails to capture the nature of refused knowledge communities: ‘Instead of an outright rejection of science and objectivity, what is involved is an effort to produce adversarial claims to objectivity and institutional supports for those claims’ (Lynch, 2020, p. 50).

RKCs’ ambivalent attitude—characterised by bitter criticism of institutional science and enthusiastic emulation of its procedures, repertoires and language—is particularly visible in the work of refused knowledge experts. As Chap. 2 by Federico Neresini illustrates, several strategies for legitimising and building epistemic authority are widespread in refused

knowledge social worlds, from boundary-work to syncretism and mimicry. Experts resort to such strategies to create and strengthen their epistemic authority.

In this context, what is particularly relevant to this chapter's topic is the fact that this compliance with the framework of practices and values typical of Western science is characteristic of the attitudes not just of experts but also of their followers. In fact, this is a sign that the turn towards refused knowledge is not dictated by a flight into the irrational, but by a profound dissatisfaction with the practice of scientific and medical research and the constraints imposed by the knowledge such research generates. The case of Davide, who is vaccine hesitant and rejects the official COVID-19 pandemic statistics, can be considered an adequate representative of the opinion of numerous interviewees.

Originally from Uruguay and father of two, Davide suffers from diabetes and hypertension and thus had to lose over 30 kilos in weight. He moved away from institutional medical advice because, he says,

today's doctors, [...] you go there, and first of all they tell you: 'What's wrong? Take these [pills], two in the morning.' It doesn't work like that. First you have to know what you eat, what you do, what you are. Try to eat less than this, and then we'll see. Don't immediately prescribe medicines. [...] That's why I started to change my life. (Davide/Pro VC)

Davide began consulting various experts on the web, thereby building his own knowledge of human metabolism and experimenting with various weight-loss stratagems. He considers it very important to rely on an expert, 'because he knows more', but he also argues that 'you need to evaluate what [the expert] tells you, not shut your eyes and say okay, I'll do this. We are capable of reasoning and saying, 'No this guy is telling me lies'. Try and try again. I tried with nutrition until I found what was right for me' (Davide/Pro VC). What was right for him was a Scientology expert and author of several YouTube videos.

Therefore, Davide's biographical turn is not a rejection of critical thinking but is based on a strengthened form of it. The fact that the experts he relies on are outsiders to the world of science originates from a profound distrust in the honesty of scientists and the impartiality of their

institutions, rather than a distrust of the scientific method per se. This attitude often relies on a distinction and juxtaposition between good and bad science, authentic science and degenerate science—the former ready to accept refused knowledge, but a minority at the institutional level, the latter hostile to refused knowledge because it is corrupted by economic interests. As Harambam has shown (2020, pp. 187–198), the opponents of science often argue that it falls far short of the ideal of sound objective science, because the connection between research findings and financial interests makes it difficult to consider scientists truly disinterested. According to the opponents of science, published scientific research is manipulated and those calling themselves scientists are traitors to the authentic scientific spirit. This attitude comes across in Davide's words, attributing responsibility for medicine's degeneration to the economic interests of pharmaceutical companies.

There is a huge interest from pharmaceutical companies in keeping patients customers. You're not dead, you're sick, we keep you there, sadly. If you die, I lose a customer; if you find an effective cure, it's not even useful. (Davide/Pro VC)

3.6 The Role of a Para-Scientific Legitimation of Knowledge

Briefly, refused knowledge social worlds refer to a widely shared model of knowledge which is basically rational and closely resembles scientific practices in its structure. It is consistent with, and leveraged by, the legitimisation strategy defined in Chap. 2 as mimicry, as it often deploys the same argumentative frameworks and scientific communication rhetoric (see, e.g., Lee et al., 2021), although it misunderstands the social dynamics that science works in accordance with and, obviously, does not share some of its contents. I will call this model of knowledge 'para-scientific' to avoid the prefix 'pseudo', as this implies a distinction between orthodox and deviant science, which is not purely descriptive and involves a normative stance (Dolby, 1979, p. 11). The prefix 'para' emphasises an affinity with science, rather than the differences from it.

Discourses supporting or justifying the transition to refused knowledge by leveraging a para-scientific model mainly pertain to three arguments: (a) the reasons for believing it; (b) the reasons for adhering to it; (c) the reasons for not believing parts of it. I will now closely examine these arguments, focusing on the stories of three 5BL interviewees—Carla, Maria and Piera.

3.6.1 Reasons for Believing in Refused Knowledge

Respondents describe refused knowledge as logical, convincing and capable of explaining situations. For example, Piera, who joined the 5BLs movement by way of anti-gymnastics, described her biographical turn in the following manner:

Anti-gymnastics helps people rediscover that the body has an intelligence. If it sends signals, these signals always make some sense. So, when I then came across the 5BLs, it clearly fitted. It all added up, taken together, and gave everything an ever richer, ever more stable meaning. (Piera/5BL)

Refused knowledge is convincing to Piera for two reasons: (1) because it is capable of making sense of the ‘signals’ coming from the world, and people’s personal experiences in particular, and (2) because it shows consistency, robustness, a capacity to explain situations in an intelligible and relatively simple manner: ‘It all added up’. This, incidentally, highlights that her discourse leverages two fundamental arguments of the classical theory of truth: correspondence (of representation to reality) and consistency (of theory in itself).

In certain cases, the intelligibility of refused knowledge takes a logical form that is typical of scientific knowledge and recognisable by laypeople. For example, Carla accords great explanatory power to the argument ‘as if’ derived from Alejandro Jodorowsky’s psychomagic (see Jodorowsky, 2010), since she sees a compelling logic in it:

I go [to the osteopath] and he tells me, ‘Your stomach is so upset because you are tense, [...] it’s as if you’re being punched in the stomach’. When

someone tells you ‘it’s as if’, he knows Hamer, don’t bullshit me! So, he said, ‘It’s as if you’re being punched in the stomach, when you get punched, what do you do? You take it!’ So, I was hunching over and I thought it was [a problem with] my shoulder, instead it was just a consequence of my posture: I took the punch and hunched up. So, she unlocked my diaphragm, straightened my stomach, and I have miraculously got straight again. In two sessions! (Carla/5BL)

While medicine often attributes discomfort to impalpable (e.g. microorganisms) or abstract (e.g. stress) causes, the unconventional explanation appears more convincing to Carla because it is more directly bound up with her personal lived experiences, such as a punch in the stomach. As Chap. 2 illustrates, this recurring refused knowledge attitude involves contrasting authentic and erroneous approaches to empirical evidence (see also Crabu et al., 2023). While the authentic method consists of appealing to experiential knowledge—i.e. the subjective, personal evidence of the individual who experiences a certain situation (illness, healing)—degenerate medicine usually resorts to statistical or experimental data, an impersonal form of knowledge which remains opaque, particularly for patients, who are not experts. Ultimately, the para-scientific model of knowledge legitimisation is based on ‘the self as the source and arbiter of all truth’ (van Zoonen, 2012, p. 56), which is the fundamental characteristic of an epistemic approach that, according to van Zoonen, is widespread in today’s popular and political cultures, but whose relevance was identified by scholars long ago as patients’ need to supplement the knowledge gained from scientific sources with their own biographical experiences (Comaroff & Maguire, 1981).

3.6.2 Reasons for Adhering to Refused Knowledge

Carla’s story introduces the second cluster of discourses in which the rational and reflective character of the turn to refused knowledge emerges: the reasons for adhering to it. While the reasons to believe in refused knowledge fall within the sphere of logic and deduction, the reasons for adhering to it pertain to the sphere of evidence and efficacy. The strongest

evidence for knowledge claims pertaining to health is obviously recovery from a disease. Thus, why turn to refused knowledge? Because it works. People agree to adapt their choices and behaviour to the dictates of refused knowledge because they feel it is effective ('I have miraculously returned straight. In two sessions!') and clearly responds to their needs. According to Maria:

it brought me to recovery [because] when I left hospital I started asking myself questions and doing research. And found out about the New Germanic Medicine. I understood that there was something else, you know, because it was like I healed myself. (Maria/5BL)

This is perceived as evidence, as she then says, 'I'm crazy, you know, but I also want the scientific thing'.

Within this narrative, the comparison with medicine is an essential step, as we have seen. People embrace a specific body of refused knowledge because it works, whereas prevailing medical treatment has not worked for them. Carla emphasises that the alternative solution worked immediately and unequivocally, while medicine does not provide definitive answers, envisages relapses and does not conceal the tentative nature of its treatment. Similarly, Piera emphasises that it works cleanly, while medicine has side effects, harms the body physically and emotionally and poisons it (with chemotherapy). In this context, Davide's comment gets straight to the point:

If I know that the results [of my own weight loss method] are good, even if the Nobel prize winner tells me it's not good, I don't give a damn, I look at this. Watch me! (Davide/Pro VC)

3.6.3 Reasons for Not Believing in Parts of Refused Knowledge

Finally, the para-scientific model of knowledge is tangible in discourses supporting the turn to refused knowledge by giving reasons not to believe in certain refused-knowledge claims. RKC adherents often place rather

precise limits on the field of knowledge worthy of trust, rejecting knowledge claims which appear to be unreliable or, at least, unconvincing, even if opposed to ('degenerate') science. Carla, who attributes great explanatory power to the 'as if' argument, considers Jodorowsky mad when he suggests stranger therapies:

For example, Jodorowsky suggests treating warts by cutting it into slices, take a red onion, cut it into slices and place the onion on the wart! (Carla/5BL)

Maria resists fully joining the 5BLs because they are not entirely clear, as she sees it:

With the [New] Germanic Medicine this is the problem: it is downplayed partly because there is little clarity in New Germanic Medicine. The reason why I am waiting to go to the [5BLs] doctor in Cosenza is precisely this—that I haven't found answers. (Maria/5BL)

Piera makes a similar point, having decided not to follow her doctor towards quantum and vibrational medicine, because this development did not 'resonate' with her:

Some things that she proposes do not resonate with me and I have never used them, I have never experienced them. For example, she is a fan of Reconnection, have you heard of it? It's a method that comes from America. (Piera/5BL)

Then she adds, implicitly explaining what it means if something does not 'resonate' with her:

Well, all these things, even the name, leave me very perplexed. (Piera/5BL)

Thus, there are several reasons not to believe in certain refused knowledge claims: because they are not plausible, barely believable, illogical, they leave people perplexed (unconvinced), and appear to lack a scientific basis. Or, finally, because refused knowledge cannot solve all kinds of

problems. While she is ready to tackle tumours through refused knowledge, Piera describes her newly acquired awareness that alternative medicines cannot solve all problems as making things clearer:

Over the years it's got clearer to me. So, today I know that if I happen to break my leg I'll go to the hospital, absolutely, and I will thank all those doctors who help me with surgery, with cortisone, or any other remedy they know to get my leg back to normal. (Piera/5BL)

Briefly, the set of practices on which the para-scientific model of knowledge is based (deductive logic, empirical evidence and systematic scepticism) closely resembles and almost replicates that of science. However, in adopting this model, those adhering to refused knowledge adopt a vision of scientific work based on the idealisation of science performed by epistemological enquiry, disregarding the more contorted trajectory taken by real science, made up of controversies and alliances, theoretical uncertainties and empirical inconsistencies, material constraints and economic drivers—a set of activities which nevertheless work well in stabilising useful knowledge.

The fact that the para-scientific model is leveraged not only by experts when they represent refused knowledge in public but also by laypeople stating their reasons for adopting refused knowledge indicates that mimicry of the scientific approach is not merely a strategy with which to strengthen one's epistemic authority and legitimise a professional field. These discourses are not merely boundary work tools but also impact on the motivations underlying individual transition processes. In other words, they shore up biographical turns.

3.7 The Moral Career of Refused-Knowledge Supporters

As we have seen, medicine is a fundamental driver in the turn to refused knowledge: it fosters adherence to the very same bodies of knowledge it deems unreliable, wrong or fake. In fact the transition is often driven by a centrifugal force that prompts people to distance themselves from

common medical practices they consider inconclusive, dangerous and dehumanising. Hence, in some respects the gradual turn to refused knowledge resembles the structuring of a moral career. Without overstating the appropriateness of this analogy, I believe that the theory of moral careers can help to highlight how science's institutional context actively participates in the process of structuring adherence to the very same knowledge it refuses. In fact, it behaves somewhat like the social institutions responsible for the social control of deviance studied by Erving Goffman (1959) and Howard Becker (1963). Like in deviance, certain social factors channel personal biographies in a direction that is by no means predetermined by the original condition of a subject and is, therefore, the outcome of processes which are superordinate to them.

To begin with, science cultivates an impersonal approach to knowledge. When knowledge is closely bound up with people's lives, as in the field of medicine and the human body, the impersonal approach cultivated and performed by doctors feels like cold indifference to people's fate, an indifference which makes scientific knowledge seem detached, distant and useless. As we have seen, hyper-specialisation and lack of empathy are aspects of medicine which interviewees stressed in their explanations of the reasons behind their adherence to refused knowledge. They create the breeding ground on which refused knowledge social worlds grow, made up of a desire for acceptance and personal relationships, a need to value personal experiences, a yearning for a harmonious relationship with one's body and a search for certain answers—all aspects which are lacking in conventional medicine and, therefore, pursued outside it.

Moreover, science boundary work confines refused knowledge to the non-scientific sphere, thereby building a wall which is then exploited by this same refused knowledge to legitimise itself as true science. In Chap. 2, Neresini argued that the boundary work necessary for the construction and maintenance of a body of knowledge involves a complementarity between what is inside and what is outside its confines. The existence of a boundary implies the existence of a territory beyond it, an 'other' social world. But this holds true in both directions. Thus, the very same boundary work by which science preserves its purity and builds its epistemic authority pushes those who feel uncomfortable with this purity to join

RKCs. This is even more evident when science takes up legal weapons, as is the case of the Italian Medical Council's authority to strike doctors failing to abide by the profession's code of ethics off the medical register. Since the register is mandatory for medical practice in Italy, the Medical Council has great power to direct the profession and put pressure on individual practitioners to meet certain standards. This power materialises in the construction of a clear and rigid border between conventional medicine and alternative forms of medicine, the latter being considered ineffective by the Council and, therefore, rejected. In our field of enquiry, this specific power of science emerges with great force in the case of the 5BLs, given that several former doctors have been struck off the Register for treating cancer patients according to the principles of New Germanic Medicine. Thus, the Council has become the main target of 5BLs experts. In a video interview published on YouTube, Paolo Sanna, a 5BLs populariser who did not complete his medical studies, has said very explicitly:

I could complete my studies now, but there are two reasons why I won't. First, because [...] I don't have the time. And, secondly, because as soon as I qualify as a doctor I would be immediately struck off, so it would be absurd, it wouldn't make any sense. Therefore, I'm studying the subject without graduating. I don't practice medicine because I'm not [a doctor], I disseminate this knowledge as an operator. (Sanna, in Ballarini, 2020)

Hence, science contributes to the structuring of RKCs. Adherence to refused knowledge is a step-by-step process in which pockets of resistance persist. This is precisely why rejection by science facilitates the structuring of a moral career: it classifies and standardises what is inherently non-standard. Not only does it exclude a certain body of knowledge from the sphere of what is legitimate thinking, but it also automatically generates the categories of pseudoscience and anti-science, which individuals are ultimately labelled with, thereby hardening what is changeable and still in the making (Bowker & Star, 2000). Moreover, this structuring effect of classification is not solely a consequence of constraints exerted externally (for example, being struck off), but also of identity-building processes (Matza, [1969] 2010, pp. 165–180). Classification implies

normalisation, generating labels by which individuals self-identify and make sense of their life paths, and creating social worlds characterised by a range of expected behaviours, shared frameworks with which members make sense of reality, and legitimate models with which they organise their experience.

In sum, it is the social interpretation of an intrinsically ambiguous experience, such as dealing with a problematic health condition, that transforms it into something definite and makes it conform to a specific pattern of action—such as embracing refused knowledge and joining an RKC. The turn to refused knowledge often originates from a ‘problem’ that finds a solution outside the canons of science. But this is just an event in life, a single experience, it still does not make definite sense. The mainstream typification of such an experience as ‘adhesion to refused knowledge’ (in common parlance, faith in pseudoscience) helps to give it recognisable meaning. Boundary work, as we have said, is reciprocal and complementary.

3.8 Conclusion

This chapter enquired into the trajectories that lead people to trust knowledge refused by science. Implicitly, I assumed that science has great epistemic authority in today’s Western societies (Hendriks et al., 2016), thus the structuring of stable forms of dissent is by no means obvious and requires explanation. I observed that the biographical turn to refused knowledge is not unforeseen and sudden, but sometimes lengthy and often complex; that this process usually passes through various knowledge terrains not accepted as valid or trustworthy by the scientific community; and that it frequently reveals a progressive radicalisation trend towards bodies of knowledge that are increasingly alternative and less compatible with recognised scientific knowledge.

I then described several drivers of this turning process and focused on the triggering role often played by specific health events in individual biographies, as well as on the reasons why medicine contributes to translating such events into ‘problems’ that only refused knowledge can help to solve. This translation of health events or conditions into problems

enables them to exert specific agency, shoring up the turn to refused knowledge. I also argued that turning processes of this kind are not normally driven by anti-scientific stances because they actually rely on a powerful faith in a simplified understanding of the scientific method based on a para-scientific interpretation of a number of practices typical of Western rationalism, such as deductive logic, empirical evidence and systematic scepticism. Finally, I attempted to interpret the role of conventional medicine in these processes in the light of the theory of moral careers in order to show that the turn to refused knowledge is not simply a matter of the characteristics of the individuals involved, nor it is only due to the RKC's magnetic force, but it must also be traced back to the structuring of individual trajectories prompted by science, in particular by medicine, precisely by virtue of its institutional nature.

This leads us on to the following concluding question: Why does the opinion of the scientific communities—i.e. of socially legitimate and especially authoritative institutions in contemporary Western societies—not deter certain people from embracing refused knowledge? The stories collected and analysed above offer a few possible answers, revealing that certain distinctive features of scientific knowledge contribute to the scientific failure to discourage those turning to refused knowledge.

Scientific knowledge is not up to expectations because it is not based on individualistic knowledge validation criteria but rather on intersubjective criteria and institutionalisation processes. Adherence to refused knowledge is often based on an epistemology which emphasises experiential knowledge. By contrast, scientific knowledge seeks legitimacy from a community of experts endowed with epistemic authority. Adherence to this type of knowledge is based on trust in this community and recognition of this authority and, therefore, requires laypeople to perform an act of entrustment, renouncing personal verification and also often accepting ideas and interpretations that conflict with their personal experiences (such as accepting the idea that the sun does not revolve around the earth). In certain cases, particularly when our health is at stake, this renunciation is no simple matter.

Moreover, scientific knowledge is not up to expectations because it is provisional and controversial by nature, which implies that scientists are used to conveying caveats regarding scientific findings. However, this is

not always welcome to laypeople, as it ‘throws individuals back on their own stock of knowledge and biographical experience’ (Bury, 1982, p. 174). As recent studies have shown, preferences regarding the sharing of information on the uncertainty of scientific results vary (Ratcliff & Wicke, 2022), with multiple audiences existing. Some of these audiences are not ready to deal with the uncertainty of knowledge. By contrast, the refused knowledge mission is frequently assertive rather than investigative, as it arises to support a stance rejected by science. Refused knowledge experts can thus deliver the certainties that orthodox scientists cannot.

Furthermore, scientific knowledge is not up to expectations because it is conveyed through impersonal forms of communication rather than interpersonal relationships. This is true, firstly, in the field of scientific writing, but it is also true of dissemination and, above all, of direct contact between experts and laypeople. Medical doctors normally put communication with patients on an impersonal plane because this is the plane on which their knowledge and epistemic authority are legitimised. Conversely, disseminators of refused knowledge often leverage emotional bonds to convey concepts and ideas.

Finally, scientific knowledge is not up to expectations to the extent that scientific institutions, which are the custodians of such knowledge, contribute to structuring the moral careers of the supporters of refused knowledge. There is a contradiction implicit in science’s role in stabilising socially useful knowledge: when it draws a boundary between what is scientific and what is not, it weakens the trustworthiness of knowledge classified as scientific in the eyes of those who consider knowledge classified as unscientific or pseudoscientific as personally useful.

In introducing this chapter, I argued that studying the transition to refused knowledge is a tool with which to increase our understanding of the stabilisation of knowledge that is accepted and legitimised by scientific communities. Indeed, the reasons leading people to refused knowledge—insofar as they are not irrational motives but replicate the scientific posture simply by translating it into alternative, para-scientific practices and reasoning—constitute a very rich basis of data and food for thought with which to revisit our understanding of science.

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4

Us and Them: Martyrs, Prophets and Mythic Narratives of Refused Knowledge

Paolo Bory 

4.1 Introduction

In the public debate, refused knowledge communities (RKC)s openly contesting the scientific community and expertise are usually labelled as marginal, fragmented and/or minoritarian aggregates of people. The claims and demands of such communities are rarely accorded space in the mainstream media, such as national newspapers and TV. Even when widespread opposition to official science is publicly acknowledged (e.g. in political debates and talk shows), it is usually depicted as the extemporary and irrational response of misinformed people to certain issues of public concern. During the COVID-19 pandemic in Italy, for example, the contestation of scientific institutions was portrayed as a spontaneous reaction triggered by fear and panic, rather than the outcome of a long-standing process by which people share everyday practices, information sources and social and cultural beliefs. During the pandemic,

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communities opposing mandatory vaccines or emergency laws, as well as alleged violations of constitutional rights and individual freedoms, were relegated—by the mainstream media in particular—to the domain of irrational, hysterical and fleeting reactions typical of the populist hype emerging in crisis contexts (Mede & Schäfer, 2020; Tomasi, 2021).

However, contrary to this partial and monolithic perspective, not only do most RKC's share certain key social practices, experiences (Crabu et al., 2022) and information on an everyday basis but the members of these communities also share stories (i.e., anecdotes, key characters and historical events) which may contribute to their epistemological and cultural foundations. Both distant and recent, these narratives provide RKC's with a set of common beliefs and reference models from the past and the present. But most of all, shared narratives bond communities more closely together, thus strengthening their members' sense of belonging, and drawing—as I will argue—on the boundaries between RKC's and other social worlds.

The purpose of this chapter is to enquire into RKC's' mythical narratives to highlight the relevance of certain key figures, events and objects around which these communities weave their common goals, visions and sense of belonging. By analysing the construction of, and tropes surrounding, mythic narratives—both scientific and religious—the sections which follow will also emphasise the ways such narratives stimulate everyday discussions, practices and even ritual forms within RKC's. In addition to martyrdom stories, a special focus on the myth surrounding Dr Ryke Geerd Hamer and the foundation of German New Medicine will also serve to display an archetypal story in which mythic science and the religious prophet trope interweave.

This chapter is divided into four sections. Section 4.1 focuses on the relationship between science, myth and narratives and shines a special spotlight on the 'mythic science' concept in historical and popular accounts of scientists' lives. Section 4.2 dwells on RKC's founding and mythical narratives, listing a series of recurring patterns characterising the RKC 'martyrs'. Section 4.3 enquires into the archetypal intertwining of mythic science and religious/prophetic narratives within one of the communities under scrutiny, the 5BLs community, also focusing on the key tropes surrounding the biography of its founder Ryke Geerd Hamer,

revolving around this prophet/scientist's revelation, conversion, persecution and exile, his commemoration and the dissemination of 'false prophets' and internal schism within the community. The last section summarises the main contents of this chapter in order to highlight the relevance of these founding and mythic narratives as bonding stories contributing, on one hand, to internal RKC cohesion and their positioning within a specific social world and, on the other, to demarcating these communities from the rest of society. As I will show, this opposition should not be understood purely from a scientific perspective but also seen in all its socio-cultural, political and anthropological diversity.

4.2 Scientific Myths, Mythic Science and Founding Narratives

In recent decades, mythical science and technology narratives have been analysed not only by historians but also in Science and Technology Studies (STS) and by media scholars, who have emphasised the importance of recurring tropes, anecdotes and characteristics of the birth, emergence and co-shaping of technologies and scientific innovations within a variety of socio-cultural contexts (e.g. Flichy, 2007; Jasanoff & Kim, 2015; Ortoleva, 2009). As these scholars argue, in common with geographical and archaeological discoveries, techno-scientific achievements and revolutions have been often narrated from the starting point of founding stories, or myths, which provide a simple explanation of certain crucial steps in the history of science and technology. Recently, in his *A Final Story*, historian Nasser Zakariya stressed the longstanding complexity of the relationship between the terms 'science' and 'myth', seeing two main ways of ensuring dialogue between the two.

On one hand, 'scientific myth' is presented as an enlightened and reasonable tale, a self-interrogated superstition, the rational submission of reason to the need for meaning' (Zakariya, 2017, p. 9). Scientific myths frequently oversimplify the process underlying scientific inquiry—for example, mishaps, mistakes and empirical or theoretical failures during research—to provide laypeople with an accessible, easy-to-understand

(and use) story. In other words, scientific myths are user-friendly strata-gems with which the history of science can be made more universally understandable, familiar and immediate. Scientific myths are generally very simple and rely to a greater extent on storytelling than the complexity and potential contradictions emerging from historical sources. Think, for example, of the anecdotes surrounding scientific discoveries, such as the apple falling on Isaac Newton's head and inspiring him with the formulation of the universal theory of gravity or of the decoding of Nazi codes by a lonely Alan Turing stubbornly working away at his Enigma machine or, once again, to the many stories surrounding the discoveries of such polyhedric geniuses as Tesla and Pasteur.¹

On the other hand, although meaningful per se, such anecdotes do not always stand alone, but can act as lynchpins for wider narratives contributing to what Zakariya labels mythic science which he sees as entailing more salient tensions and cultural resonances. Mythic science is an already tamed, if multivalent phrase, the adjectival form of myth bearing little suggestion of 'objectively false', but rather the sense of 'epically scaled' or 'famously successful' (Zakariya, 2017, p. 9).

Mythic science is based on more than simply anecdotes and stories emphasising the ingenuity of inventors and scientific figures but also showcases a longer, more troubled story of struggle between geniuses and their theories/discoveries and a hostile system which, in order to preserve the status quo, even went as far as rejecting the clear empirical proof he provided. In this regard, mythic science presents scientific achievements and innovations as an epic fight between brilliant minds and a system that resists the threat they pose to normal science, and not only on the scientific but also on the political and economic interest planes. There is nothing accidental about the fact that, in narrative terms, mythic science usually melds with epic, for example hybridising inventors' histories with the hero's journey narrative trope (Natale & Bory, 2017), as outlined by Joseph Campbell in his famous book on recurring patterns in worldwide mythologies and epics (2008).

¹ The life of Pasteur is a case in point of the struggle between scientific myths and mythical science and historical enquiry (see Cavaillon & Legout, 2022; Latour, 1987).

On their part, historians have bitterly criticised the production and dissemination of these narratives. For example, Douglas Allchin (2004) labelled scientific myths ‘pseudo-histories’, comparing the lack of reliability of their sources to the empirical fallacies of pseudoscience. By contrast, several authors have emphasised that myths and, in turn, mythic science should be read through a range of lenses. Rather than seeing these narratives as false or fictional tales, it is more helpful to shed light on the meanings conveyed by founding myths and narratives, especially the possible reasons underlying their long-term persistence in the social imaginary. In this regard, since myths are socio-cultural sense-making tools, they act as ‘bridges between the human and the cosmos’ (Ortoleva, 2019) and should be studied less in true/false dichotomy terms than as living or dead beliefs (Mosco, 2005) prevailing over historical enquiry or empirical revisionism.²

Where RKC's are concerned, scientific myths, and mythic science in particular, are extremely widespread and serve as precious narrative resources within their social worlds. For example, certain key mythic science concepts are used as analogies with which to justify these communities' struggle with the academic, economic and political elites preserving the status quo. In the Italian RKC social world, influential figures such as Giordano Bruno and Galileo Galilei are often described as RKC predecessors whose aim is to overturn current conceptions of science and scientific truths. It is worth noting that, unlike other prominent figures in the history of science, these men failed to reach their goals during their lifetimes. It is this which makes them not only heroes but also martyrs. They died or were punished—both psychologically and otherwise—for bearing witness to a faith or an idea. This contributes to a key demarcation between the founding narratives of certain RKC's and mythic science: As I will show, the stories surrounding RKC's' best-known characters—particularly those of the 5BLs community—and what is portrayed as the final destiny of most of their members, tend to conflate

²It is worth noting that mythical science also serves scientific communities, keeping their social worlds tightly bound up. For example, rituals and celebrations such as annual prizes and global events in honor of history of science heroes are a clear demonstration of the relevance of these figures to scientific community self-identification, thereby contributing to the mythologising of great scientists.

epic with religious content, thereby hybridising the hero and martyrdom and religious prophet tropes.

4.3 The Martyrs of Refused Knowledge

Like Bruno and Galilei, three of the mythical characters of the communities under scrutiny in this book have been rejected by the scientific community as well as publicly and formally condemned by the scientific and legal institutions by means of ‘exemplary punishments’. Dr Robert O. Young, one of the key figures in the alkaline water community and author of the ‘pH Miracle’ series of books, was convicted of several crimes relating to practicing medicine without a license and widely discredited in traditional media. Andrew Wakefield—a key Pro Vax Choice community figure globally famous for his theory regarding the link between autism and MPR vaccinations—has been repeatedly attacked in magazines, newspapers and TV shows and was struck off the medical registers in both the UK and the US. In addition, Dr Ryke Geerd Hamer, the founder of the German New Medicine movement based on the 5BLs, lost his license to practice medicine in several European countries, was jailed in Germany and served a prison term in France for fraud and unlicensed medical practice. From the RKC perspective, all these public and formal punishments go hand-in-hand with the sacrifice that goes along with protecting not only their discoveries but also their moral and ethical values and, in turn, the community they belong to and represent.

Furthermore, these stories go far beyond contingency. Public condemnation of what the scientific community sees as quackery, or pseudo or mock science, can trigger a boomerang response by RKC. Sometimes with the support of media and political influencers, such communities (Bory et al., 2022) generate brand new content and materials—such as petitions, documentaries and counterfactual documentations—to debunk the legal and scientific proofs which discredit their founders and martyrs. Occasionally, RKC martyrs promote and distribute new materials regarding their unjust persecution, as in the case of the documentary *Vaxxed—From Cover-Up to Catastrophe*, produced and directed by Andrew Wakefield in 2016 to demonstrate the accuracy of his research

on the relationship between vaccines and autism, which circulated widely on social media platforms and is still a ‘must-see’ for the Pro Vax Choice community in Italy and abroad.³ This chain reaction between exemplary punishments and the production of counterfactual evidence underlies the construction of martyr figures like Wakefield.

However, martyrs are not necessarily transnational figures. They can also emerge in local or national contexts. All the figures mentioned above are reference models or founding fathers of RKC in the West. However, in addition to internationally recognised men such as Wakefield, Young and Hamer, RKC also have local and context-specific leaders who occasionally perform the same roles as mainstream international figures. Maurizio Martucci, one of the leading figures of the Italian Stop 5G scene, is a clear example of a leader who also acts as spiritual guide. Martucci’s struggle against 5G in Italy is, in fact, not only political but also has a strong spiritual connotation which sees technocracy as contrary to mother nature’s rules and inner dynamics. Thus, there is nothing accidental about the fact that, in his bio, Martucci describes himself as leader of Alleanza Italiana Stop 5G, and also a holistic discipline and age-old tradition enthusiast who practices Kundalini Yoga combined with an interest in the spiritual path taken by native peoples in symbiosis with nature. [...] He is the founder of the natural information website OasiSana (AT: Healthy Oasis).^{4,5}

Other Italian communities, such as Pro Vax Choice, together with a series of political and leaders generally labelled populist, rely on certain exemplary cases or genealogical anecdotes from the past. Some of these stories have made vaccination hesitancy history in the Italian context. An example of this is the story of the Tremante family, a major vaccination controversy, which made Italian news headlines from the 1970s onwards. After the death of his first child in 1971, Giorgio Tremante lost two more

³ The sequel to *Vaxxed*, *Vaxxed 2*, was directed by Robert Kennedy Jr, the son of another US political history’s martyrs and well known for his anti-vaccination beliefs and promotional campaigns worldwide.

⁴ <https://www.terranuovalibri.it/autore/maurizio-martucci-182514.html> (accessed 6 October 2022). For an overview of Martucci’s role, see Simone Tosoni’s chapter in this book.

⁵ From now on, all text excerpts from Italian blogs and websites, and in-depth interviews are translated by the author.

children, and another remained paraplegic, because of the adverse effects of mandatory vaccinations.⁶ After 14 years of legal battles, Tremante received state compensation for his children's deaths but no compensation for the damage, for which he filed an appeal at the European Court of Justice which is still awaiting trial. This exemplary story of loss, suffering and legal battles eventually led to the foundation of Comilva, one of Italy's most active associations against mandatory vaccinations.

If the Tremante case is specific to the Pro Vax Choice community, occasionally martyrs succeed in crossing the RKC boundaries into other RKCs, constituting temporary symbols in a common struggle for one social world (centred on various forms of refused knowledge) as opposed to another (usually led by the academic and scientific élites). For example, during the COVID-19 pandemic, Italian doctor Giuseppe de Donno promoted an alternative cure based on the transfusion of plasma from healed to ill patients. De Donno argued that this would cost much less than other forms of treatment and would allow nation-states to remain independent of the oligopoly of pharmaceutical companies. Eventually this 'plasma-based cure' was rejected by the scientific community on the grounds that there was no empirical proof or statistical data indicating that it worked (RECOVERY Collaborative Group, 2021). Concurrently, a few RKCs, such as the Pro Vax Choice community, began promoting the plasma cure as the 'people's cure for the people' as opposed to the vaccines, which were simply filling Big Pharma's pockets. The plasma cure became a miracle artefact amplifying the centrality and public aura of its discoverer. In narrative terms, the miracle cure-persecuted scientist combination eventually spawned a new martyr. In fact, a few months after the public rejection of his findings, De Donno committed suicide in his apartment. Shortly before his death his profile had been censored by social media platforms such as Facebook and he had been sidelined by the Italian scientific and medical communities. Beginning on the day after his suicide, De Donno was hailed as a martyr by various communities, and became the human embodiment of the public value of the

⁶On his website, named 'Holocaust caused by vaccination practices' and displaying the dates of his children's deaths, Tremante has published all the articles and parliamentary questions regarding his legal case and other vaccine-related legal issues. See: <http://www.tremante.it/> (accessed 6 October 2022).

sacred/miraculous artefact. De Donno's suicide was described on RKC social media as suspicious with some users suggesting that he had probably been assassinated by the scientific/political élite to 'eliminate' a potential enemy. De Donno's sacrifice ultimately made him a symbol for numerous RKC's of the struggle for 'truth' against the power of the scientific and political establishment.⁷ It should be noted that not all RKC's reacted in the same way to this episode. The 5BLs community, for example, did not endorse the cures proposed by De Donno, but honoured his lonely fight against the 'system', while other communities agreed on the presumed evidence for the efficacy of the 'plasma-based cure'. Like De Donno, notwithstanding the diversity in their epistemic backgrounds, all the characters associated with RKC's—such as Hamer, Wakefield, Young and many others—are fighting together in the front line of a shared struggle against scientific elites. It should be noted that, unlike global martyrs such as Wakefield, the stories such those of Tremante and De Donno are 'common man' stories of people heroically fighting for their rights, generating a mythical aura that is as powerful as other more common martyrdom stories.

4.4 In the Name of the Prophet: The Ryke Geerd Hamer Archetype and the Birth of the Five Biological Laws Community

In the RKC social world, certain myths have taken on such importance that they resemble the foundational myths which have long characterised human history and have occasionally equated scientific myth with sacred myth in a hybrid part-scientific-genius-part-prophet system. This is the case of Hamer and the five biological laws. Of the numerous founding narratives of the Italian RKC's, the story of the discovery of the 5 Biological Laws (5BLs) is probably the most archetypal and fascinating. All the

⁷False prophets emerged during the pandemic as well. An example is Pasquale Bacco, one of the doctors who led the campaign against COVID vaccinations in 2020 and then changed his mind in 2021, withdrawing all his previous statements and making himself a 'common enemy' for several RKC's.

founding narrative traits and tropes listed thus far conflate in the mythical figure of German doctor Ryke Geerd Hamer, founder of German New Medicine (GNM), a blend of scientific epic and spiritual implications, combining the story of a great scientist with the life of a prophet.⁸ Scientific myth narrative tropes such as the eureka moment and scientists' fight for public acknowledgement of their discoveries are there in Hamer's life story, together with certain key life-of-the-prophets tropes. To summarise the stages in the prophet's journey, four tropes will be analysed in this section: revelation, conversion, persecution and exile, and the fight of the prophet and his followers against 'false prophets'.

4.4.1 Revelation

In 1978, while on vacation in Corsica, Ryke Geerd Hamer's 19-year-old son Dirk was shot in the leg by Vittorio Emanuele di Savoia, the former Italian crown prince. Dirk Hamer eventually died, and his father was later diagnosed with testicular cancer, which was operated on. Following these episodes, Hamer dreamt of his son, who guided him to the discovery that cancer is caused by sudden trauma leading to biological conflict. In 1981, Hamer elaborated a theory according to which all diseases are caused by biological conflicts and only profound understanding of the origin of the disease and, thus, of the conflict itself can bring healing. He called this process the Dirk-Hamer-Syndrome (DHS) in homage to his son, thereby baptising the Five Biological Laws (5BLs). Hamer credits his son's appearance in his dreams for his discovery of the 5BLs. On one hand, Dirk's appearance in his father's dreams can be seen as a form of hierophany (Eliade, 1963)—i.e. a manifestation of the sacred. The hierophany of Dirk Hamer partially fits with other anecdotes like the

⁸The scientist/prophet dichotomy has already been examined in rhetorical and historical studies (Lessl, 2011; Walsh, 2013). For example, in her book *Scientists as Prophets* (2013), Lynda Walsh points to the prophetic role of contemporary scientists, analysing the scientific rhetoric used. According to Walsh, contemporary 'great' scientists tend to not only forecast the future of society to strengthen their scientific paradigms and discoveries but also to disseminate their personal views on political and societal issues. Unlike Walsh's contribution, the scientist/prophet parallel used in this chapter focuses more on the religious features and narrative tropes surrounding the stories and prophets and thus not only on their role as 'oracles' (Walsh, 2013, pp. 160-161), which is mainly based on their claims to foresee the future.

annunciation of Christ to Mary by Archangel Gabriel or the finding of the Tablets of Stone in the Moses story. However, unlike these examples, Dirk did not reveal everything about the natural laws to his father, but provided his father with a series of clues and scientific paths to it, for example,

this [the 5BLs] will cause a revolution in medicine. You can publish it in my name. But you will have to do more research. You haven't understood everything, you are missing two important things. (Post on Facebook from Hamer's testament, published on 17 March 2022)

According to this story, Dirk's revelation of the laws was not self-explanatory. As a scientist Geerd Hamer had to follow his son's advice and study, research and prove the validity of the laws. This revelation story had a great impact on the 5BLs community. On one hand, Hamer was not the creator of the laws, but rather the scientist who translated the laws provided by Dirk for the people. In Geerd Hamer's words,

my Dirk deserves credit for not only initiating the knowledge of cancer correlations through his death, but also inducing it after his death and passing it on to me. (ibidem)

The character of the son Dirk is essential to the 5BLs community, since he was both the first source and the depository, it might be said, of the 5BLs copyright. It is no accident that his picture is everywhere on GNM followers' social media profiles and several magazines and books on GNM display Dirk's picture on their covers. However, if Dirk is the 5BLs saint, Ryke Geerd Hamer is the medium capable of conveying his word and simultaneously the scientist required to test and disseminate the laws and make them understandable and verifiable worldwide.

4.4.2 Conversion and Persecution

Ryke Geerd Hamer's background was in theology and medicine. It is no accident that religious and scientific reasoning and wordings are often

used side-by-side in his writings. After the 5BLs discovery/revelation, Hamer took another important step along the path taken by many prophets: conversion to a new medicine and rejection of orthodox medicine and the elitist organisation of which Hamer himself was part. In fact, Hamer's conversion to German New Medicine went hand in hand with bitter criticism of medical practices and protocols and also of the medical establishment's organisations and infrastructures, such as hospitals and psychiatric facilities. Such criticisms were juxtaposed to a spiritual and evangelical mission: to help the weakest, poorest and most unfortunate victims of a cruel and dehumanised medical system. For example, in his account of a visit to a psychiatric hospital, Hamer argued that what I saw there was dreadful and horrific. Patients, including young people with schizophrenia, who had dreams and hopes like you and I, were sitting in a closed facility like animals in a cage. Nobody knew what diseases these unfortunate people really had. Since that time, I had the strong desire to help those poorest of the poor. I believe that I have succeeded. (Hamer, 1987, p. 3)

Hamer's mission and conversion is consistent with those of other prominent figures in the history of prophets. Think of the story of Siddhartha, born into a wealthy family as a prince but moved by the world's suffering to give up his wealth for a life of poverty and help people find the true path to spiritual balance. Similarly, Hamer gave up his wealthy and authoritative role in orthodox medicine to help those in need. But, once again, this religious conversion conflates with a radical change in scientific practice, leading Hamer to a new vision regarding the role of technology in medical practice. Notably, Hamer's redemption from orthodox medicine went hand in hand with a shift from a hyper-technological job to a medical practice that excluded most medical artefacts and technologies. The founding narrative recounts that before his conversion to 5BLs, Hamer was famous for patenting and selling innovative surgical instruments. Once redeemed from cold allopathic medicine, he was to use medical instruments—for example, X-ray machines—only to demonstrate the validity of his theories, while rejecting and condemning most of orthodox medicine's technological and pharmacological

applications.⁹ This paradigm shift led Hamer to condemn medical practices such as chemotherapy on the grounds that they interfere with the natural progression of diseases. This rejection of technocratic medicine resonates in the discussions and posts of the 5BLs community, both orthodox and more flexible. For the 5BLs community, on top of various criticisms of vaccines, chemotherapy and other specific technologies, the entire spectrum of allopathic medicine is also to be condemned:

The average man continues to throw down pills for high blood pressure, blood sugar, cholesterol, prostate, and a variety of other reasons, without having any knowledge of the substances and their real 'usefulness', out of sheer confidence. And he continues to undergo often humiliating and invasive examinations, performed with increasingly cold and sophisticated machinery, out of sheer confidence. (AT Blog post by 5BLs expert, 20 June 2020)

The conversion to 5BLs and rejection of the 'cold and sophisticated machinery' specific to orthodox medicine was followed by a long series of trips and experiences through which Hamer evangelised his medicine, triggering a powerful reaction from the scientific community which, according to the narrative, began persecuting him all over Europe:

In Chambéry and other places there were people coming from Spain and from Italy, you could see the queue of patients on three floors: and then he was convicted of illegal practice of medicine, you know? I witnessed all this process, and I saw how nobody listened to him. Eventually, they tried to kill him: he has a bullet hole in the windshield of the car. They tried to intern and lock him in an asylum. And, so, in short, my belief was at that time that Hamer was slandered, also because he had a view of the whole scientific world that was appealing to his findings, saying that they were Jewish Masonic lodges. (Interview with 5BLs expert)

The persecution of Hamer, like those of religious prophets such as Christ or Jeremiah, turned into a series of official and exemplary

⁹In particular, German New Medicine is against chemotherapy as a cure for cancer and also condemns the use of various forms of analgesics (particularly morphine) because they interfere with mental processes and are dangerous to patients' health.

condemnations. Hamer was jailed, colleagues from various countries criticised and publicly condemned his earlier work and he was disbarred from the medical profession and attacked by the mainstream media, especially in Italy. The boomerang effect of this multipronged attack is that today, according to orthodox GNM followers, medical experts should follow Hamer, despite the risks involved:

From the outside, one practically expects that the system to which one belongs by duty, and with which one does not interact, must at some point implode. Hamerian doctors must ask to be disbarred and get out of the system to be honest with themselves. (Blog post by 5BLs expert 20 June 2020)

Furthermore, Hamer's conversion, subsequent persecution and consequent pain and suffering make the scientist/prophet extremely 'human', suggesting that anyone, not only scientists and doctors, can change their minds about health and medicine—irrespective of their age—and embrace the 'truth' revealed by the biological laws.

4.4.3 Exile, Death and Commemoration

Certain prophets' narratives end with a death penalty. When Hamer was persecuted, some members of the 5BLs community even went as far as to hope for such an end. Again, recalling the life of Galileo, one member of the community claimed

Even Galileo was targeted for his discoveries and yet it is still the earth that revolves around the sun. If we want to get to the juice, indeed, at the moment of the squeeze we discover that it is still 'love that moves the sun and other stars'. Why don't they just kill him and end this for good? I think the power that would create a martyr of this magnitude is truly infinite. (Posted by 5BLs member on Facebook group 12 December 2016)

However, Hamer was never killed. The last part of his biography led him to another prophet trope, his lonely exile in Norway to take refuge against all the trials, journalists and other potential persecution from the European scientific establishment. Soon, Hamer's home in exile became

a place of pilgrimage and the followers of German New Medicine attempted on various occasions to reach out to the prophet, meet him and listen to his truth-speaking voice live. It is no accident that Hamer interviews during his exile, some of which are still available on YouTube, have become key social media content shared by the members of the 5BLs community. Even today, the followers of German New Medicine frequently discuss, re-post and comment not only on Hamer's medical and scientific thought but also his incredible ability to foretell the future, as with the dangerous and elitist project that eventually led to the pandemic vaccination campaign.

The scientist/prophet in exile must be met, touched and listened to by his followers, and this is exactly what three young members of the 5BLs community did when they embarked on a long trip to Hamer's house in Norway the following manner:

We are three friends, three colleagues, three scholars who have decided to draw from the source, the fundamental, the essential substrate, the energy behind the discovery. [...] The target is Norway, the target is a doctor, or rather, The doctor. I'm talking about Dr Hamer himself. [...] I want to give this diary a magical and mystical note, as this journey has been and will be, magical and mystical. We are so grateful to Dr Hamer that despite the complexity of the situation we will pay visit to him without knowing if he will open the door. But we will meet him, despite all the obstacles ahead, we are too determined. (From the diary *A Discovery Journey to the Source*, published on 5BLs Facebook groups)

The last mass pilgrimage to Hamer took place in July 2017. On 2 July Hamer died of a stroke and recordings of his funeral on 14 July 2017 show hundreds of people attending a magnificent event whose ritual solemnity and sacredness were enhanced with flags, choruses and testimony. After his death, Hamer became both GNM and the wider 5BLs community prophet and martyr. Every year, on 2 July, members of the 5BLs community share Hamer's picture on social media accompanied by the words 'Thank you Dr Hamer',¹⁰ and prayers and comments on their

¹⁰ *Thank you, Dr Hamer* is also the title of the most widespread and prominent Italian book about GNM.

founder's greatness, goodness and profound kindness and humanity. Once again, in this ritual, the prophetic and mythic science narratives conflate, as users' posts like the one below show:

Ryke Geerd Hamer (Mettmann, 17 May 1935–Sandefjord, 2 July 2017)

Man, Doctor, Genius, Martyr.

(Posted 2 July 2021 by 5BLs expert on a Facebook group)

This moment of commemoration has a twofold meaning. On one hand, the community congregated around its founder, commemorating him for his gift of the 5BLs. At the same time, as Marcel Mauss argued in his anthropology classic (Mauss, 1990), every gift brings with it the donor's identity and his human values. Commemorating Hamer's death serves both to give the community cohesion—it is a ritual of communitarian reunion—and facilitate the sharing of values and attitudes and a shared struggle against the status quo. Like Hamer, 5BLs followers have a mission to accomplish—to assert their right as human beings to return to nature, follow its rules and oppose elitist control over health and medicine practices by a small number of cold actors and technocratic institutions.¹¹

4.4.4 Schism and False Prophets

Prophets' biographies generally discuss their struggles against those who attempt to mimic and overturn their teachings. False prophets are presented as impostors or traitors who distort the 'word of God', as in Catholicism's apocryphal gospels. This kind of struggle for the truth is also visible in certain scientific controversies, particularly when scientists and inventors dispute their origins and empirical proof.

In certain cases, false prophets find their own followers who launch a new version of the cult, thereby provoking a schism that splinters the original community. Within the 5BLs framework, false prophets are guilty of three major sins: misinterpreting or mixing the laws with other

¹¹ On this topic, see Stefano Crabu's chapter in this book.

false claims; portraying themselves as new prophets, usually overshadowing the true prophet Hamer; enriching themselves with the sacred word and misappropriating the biological laws from their collective ownership.

Towards the end of Hamer's life and after his death, a number of adepts decided to establish their own schools and training programmes, triggering an internecine struggle within the community. Hamer himself disavowed a few of his pupils, particularly in Italy.¹² For example, in a letter to the members of the first Italian 5BLs association named *Associazione Leggi Biologiche Applicate—Association of Applied Biological Laws* (ALBA) Hamer wrote,

I want to have nothing more to do with the superiors of ALBA, who have betrayed me, the German New Medicine, and deceived our patients (by 'superior order?'). [...] I consequently formally forbid ALBA executives, to defraud me and all patients in my name and under the banner of the German New Medicine. (Letter from Hamer to the members of ALBA, 16 March 2007)

Although the movement's founder/prophet has never been questioned as such by any associations or training schools promoting the biological laws, three sub-groups relying on Hamer's work but with various degrees of flexibility can be distinguished. The first, and probably the most apocryphal, of these, and also the largest, is made up of people who rely only partially on the 5BLs—for example, adding and mixing the contents of GNM to allopathic medicine or to other approaches such as Chinese traditional medicine and homeopathy, among others. For these people, Hamer is one of many charismatic figures who have contributed to individuals' emancipation from a monolithic and elitist vision of medicine and science.

The second can be labelled progressive and is led by a series of 5BLs experts, most of whom have a research background in fields such as psychology and alternative and/or complementary medicines. This group, like most scientific communities, aims to promote Hamer's discoveries and combine the 5BLs with other approaches, whilst retaining 5BLs as

¹²Hamer condemned one of his pupils in particular. The dissemination of false prophets here conflates with another recurring trope of religious stories: the betrayer, the Judas.

the cornerstone of medicine. Some of these figures—many of whom have renamed GNM, thus hiding Hamer's name from their promotional campaigns—claim that GNM, like science, needs to be explored further. Some of the progressives have been bitterly criticised by other followers of GNM, mainly on the basis of accusations that they are attempting not only to appropriate 5BLs but also to make money from it:

There are people who have based their wealth, their income, on the use of this information. (Sighs) Which is ok, it's not wrong to want to make money or create an economy around this thing; however, what I regret is not seeing anything given away. Nothing freely donated. That is, the five laws are a heritage of nature, they are not a copyright. They are not a patent! They are not patentable. It's like wanting to patent gravitation, you know? I mean gravitation is gravitation. Whether you are walking or flying, there is always gravitation. And it's not patentable, so why do you keep it for yourself? All for yourself? I don't understand that. (Interview with 5BLs expert)

The third group can be labelled the orthodox group—that is, those who trust and follow only Hamer's first-hand writings and lessons. This group generally criticises false prophets, particularly those who attempt to 'update' the 'already perfect' GNM:

There are two methods of spreading the GNM: in one we talk about the 5BLs, we never go against official medicine (on the contrary, the GNM integrates...), the 5BLs (which have no therapy) are mixed with the most disparate alternative 'therapies', and very little (practically never) is said about Hamer. And in this modality, the new gurus are created, those who 'know', who 'save you', and who are protected by the adepts in a stupid and childish way [...]. It is the same modality of the patient-doctor relationship in official medicine. In the second method, we talk about Hamer's medicine, we talk about the propaganda, the lies, and the idiocy of the official medicine; we do not mix the GNM with anything else because there is no need for that, because the SBS programs are already a therapy—the therapy of nature. (Blog posted by 5BLs expert on 20 September 2020)

This dispute between adepts and false prophets notwithstanding, the prophet and great scientist trope that is the cornerstone of GNM contributes to the very survival of this approach. The Hamer founding narrative ensures that the 5BLs are always discussed, reinterpreted and, in certain cases, questioned and updated. In this regard, rather than generating a paradigmatic shift in the 5BLs community the schism led only to a partial evolution in its genealogy, thereby widening its potential audience into new types of followers.

As one of its experts has argued, the most important schism in the 5BLs community in Italy notwithstanding, the biological laws will never disappear:

Five minutes after the advent of all the greats of the earth, the most disparate truth-claiming groups were formed within the very core of innovative thinking. Thus Christ's birth was followed by that of the Catholics, Protestants, Calvinists, Orthodox, Lutherans, Mormons [...]: all claiming to have the best God. [...] So, we have a God for Muslims, for Orientals, etc. [...] So it happens a little bit to all currents of thought. [...] As far as Hamer's findings are concerned, I feel particularly calm, because biological laws do not give a damn about internal divisions and, since they are laws that have always existed and will always exist, they fortunately continue to apply as natural processes. (Trupiano, 2015, p. 284)

Overall, the truth of the 5BLs will always prevail in any forms of schism. Just like scientific and religious myths, scientific truth and holy truth go hand in hand. The comparison with religious systems here is not coincidental: like God, the laws of nature survive any kind of 'truth-claiming groups', and false prophets cannot even scratch the surface of the truth.

4.5 Between Us and Them

The archetypal Hamer story, and the melding of mythic science with prophets, is a clear example of the contribution a founding narrative can make to the creation, stability and preservation of an RKC over time. In this narrative, ingenuity, spirituality, epics and sacredness are mixed up

together, following tropes regarding scientific achievements alongside religious contents, rituals and internecine conflict between the community's followers. On one hand, the power of such narratives lies in their shareability and familiarity, in other words, its set of recurring patterns, metaphors and figures which constitute the building blocks of epics and religious texts worldwide. On the other hand, additional intricacy, complexity and concurrent forms of resistance within the 5BLs community to external epistemologies go hand in hand with the quality, recognisability and solidity of its founding narrative regarding its scientist/prophet Hamer.

Simultaneously, other communities such as Stop 5G, Alkaline Water and the Pro Vax Choice community also have their own founding narratives and martyrs. However, these communities often recall their founding fathers, martyrs and key anecdotes in a more functional manner, depending on the struggle under way or the enemy targeted, as in the last pandemic. Unlike transitory martyrs (e.g. De Donno during the pandemic), founding fathers are heroes and, simultaneously, martyrs representing a common mission to revolutionise not only science, health and medicine but also politics and culture. In this regard, the 'us' and 'them' dichotomy is summed up by these characters and their biographical journeys, thereby also leveraging another recurring prophetic narrative trope—millennialism. Notably, founding fathers (and very rarely mothers) and legendary scientists—such as Galileo Galilei and Giordano Bruno—often do not achieve their goals. Rather, they anticipate and contribute to a long-term achievement that can be either a full 'evangelisation' of society or, more often in RKC, an apocalypse, a final judgement, in which those who 'know' or have learned 'the truth' will be saved. Whilst the words they use may vary contemporary RKC prophets and leaders recursively share a common philosophy: 'As far as we know, our community will survive, while they will eventually pay or perish'.¹³ In a

¹³This is a rhetoric characteristic not only of scientific and religious beliefs but also of conspiracy theories and populist narratives. In a sense, in RKC as well as in science-related populism, the religious discourse revolving around the final judgement, according to which 'those without sin will be saved', intersects the resistance rhetoric found in political movements (e.g. partisan movements) and according to which the final liberation of the people will depend not only on an 'act of faith' but also on a daily struggle for survival or, in other words, on a constant act of 'resistance'. The fact that the social world of refused knowledge communities appears to subsume religious beliefs and political views into a single system of thought and belonging certainly requires further analysis and empirical research, from both sociological and historical perspectives.

motivational post at the beginning of the pandemic, the most prominent Italian magazine on the 5BLs claimed:

The crisis is not now, the crisis will not be later: think about it, the crisis started long before this phenomenon. We recognised it but we always gritted our teeth to adapt and survive and not only in economic terms. Before our life was survival not life, now our life is an opportunity to start living again, to change how our world works. Not with manifestations but by individually raising our vibrations. If we allow ourselves to transcend the manifestation of current reality and keep our new reality intentions for the future alive, on a daily basis, we have the ability and all the necessary talent to create it. The ‘how’ will present itself at the right time along our way with new opportunities, new ideas and new actions which have never been tried before. If you are listening to this, it is because you have already set off on your personal path, also thanks to the five biological laws. Now there is nothing you can do because you have already acquired the tools, and earned them with the sweat of your brow. (Posted on 5BLs Magazine on 18 April 2020)

As this quote shows, the pandemic amplified millennialism’s discursive presence as one of the most recurring tropes in RKC’s and several religions worldwide (Lynch et al., 2021; Murru, 2022). Notably, the ‘us and them’ dichotomy is also a demarcation between those who believe in the inner eschatology of their scientific, but also cultural and religious, paradigms and those who will be condemned for following the ‘false prophets’ of dogmatic science. Founding narratives, the martyrdom stories, prophecies of a future in which orthodox science will be overturned by a pure and human-centred science—these are all part of a common action plan designed to separate RKC’s off from the rest of society, not only in scientific but also in shared belief terms and, in turn, of political views and everyday behaviours. As Claude Levi-Strauss argued in his seminal study (2013), myths are designed to resolve the inner contradictions and uncertainties of a specific society or community. Overall, the understanding of the values and the exquisitely political meanings of RKC mythical systems will not merely serve to bring down the refused knowledge ‘house of cards’ (i.e. revealing its ‘false’ myths). Such understanding is rather essential to shed light on what the house is built on, and also to explore the vulnerabilities, inadequacies, contradictions and communicative biases of contemporary science and of scientific narratives.

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5

From Scientific to Syncretic Patchwork Storytelling: The Discursive Ecosystem of Italian Stop 5G Refused Knowledge Communities

Simone Tosoni 

5.1 Introduction

The relationship between RKC as social worlds (Clarke & Star 2007; see also Chap. 2 by Federico Neresini) and the knowledge they profess must be conceived as inherently co-constitutive. On one hand, sharing knowledge refused by the scientific community constitutes RKC's 'principal affiliative mechanism', 'both making and marking [their] boundaries' (Clarke & Star, 2007, p. 115). It is sharing a common system of beliefs which prompts individuals to join these groups, keeps RKC together and potentially accords members specific expertise-based status. On the other hand, this knowledge is not unchanging and pre-existing members' participation, but both pre-condition and outcome of their participation

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itself: it is continuously produced and reproduced by RKC's themselves through ongoing discoursivisation practices performed in a range of 'situations' across a plurality of sites (Clarke, 2005). This is the case, for example, of live meetings or social media debates to which members contribute with new information or by contesting certain assumptions in favour of others. It is also the case of the production of articles, books, videos and other cultural artefacts in which RKC's shared knowledge achieves a higher level of systematisation, becoming, however temporarily, more stable.

It is precisely to account for this co-constitutive relationship that the social worlds framework (SWF) moves beyond 'concepts of discourse analysis stemming from European phenomenology and critical theory' (Clarke & Star, 2007, p. 116) to address the discursive production situation (Strübing, 2019) where the social world and its discourses are simultaneously shaped. To this end, it adopts an ecological approach that conceives of the situatedness of social discourse production in an relational way, that is, as a form of interaction between a plurality of social actors and nonhuman actants (such as social platforms' algorithms, for example) participating to the same social world, and to the wider arena revolving around the same 'matter of concern' (Latour, 2004). Notably,

All the elements empirically found in the situation of interest [...] are understood as co-constitutive—they help to make each other up and together constitute the situation as a whole [:] things have meaning only in relation to the situations in which they are found or occur. (Clarke, 2019, p. 15)

In what follows, I will adopt this perspective to address the discursive knowledge-production situations enacted by the Italian Stop 5G RKC throughout its history. This case study is, in fact, especially revealing regarding the 'situatedness and contingency, history and fluidity, and commitment and change' (Clarke & Star, 2007, p. 113) of the co-constitutive relationship between RKC's and their shared knowledge. In particular, I will focus on the strategies adopted by the Stop 5G RKC to mark the boundaries of its discursive practices in order to stabilise its shared knowledge, and the radical changes that took place in these practices during the COVID-19 pandemic. I will describe this turn—which

is currently risking breaking this RKC up—in terms of a shift from a ‘scientific’ to a ‘syncretic’ patchwork storytelling approach, the former based on selecting sources regarded as scientific, the latter combining diverse and sometimes conflicting discursive sources, such as scientific knowledge, folklore, new age spirituality and conspiracy theories.

It is, however, impossible to address this turn without paying systematic attention to the role played by media—and social media in particular—in the concrete discursive knowledge production situation analysed here. As we will see, a significant part of RKC discursive practices are media-related (Couldry, 2004, 2012) and became exclusively so during the COVID-19 pandemic lockdown. Before we proceed further then, we need to adapt a methodological framework from media studies to support the ecological approach advocated by the SWF when dealing with media-related practices.

5.2 A Media Ecosystem Approach to RKC Discursive Shared Belief Production

Over the last two decades, an ecological methodological sensibility has emerged in various subfields of research within media studies (such as journalism studies, media archaeology and media storytelling studies), prompting scholars to move beyond approaches centred on a single medium and an overly rigid compartmentalisation of their research interests into user-, content- and technology-related issues (Anderson, 2016; Fuller, 2005; Pescatore, 2018; Taffel, 2019; Zuckerman, 2021). However differently—and sometimes inconsistently—understood by the various authors, the concepts of (media/news/narrative) ecology and (media/news/narrative) ecosystems have been leveraged to acknowledge that media phenomena can only be tackled in a relational way, as an interplay of heterogeneous and mutually constitutive entities (Tosoni & Tarantino, 2013): symbolic and material, human and nonhuman, pragmatic and structural, and social, economic and technological.

This *rhizomatic* approach to media ecology, which should not be confused with the *environmental* media ecology tradition stemming from the work of Marshal McLuhan and Neil Postman (Anderson, 2016),

developed independently of the SWF. Nonetheless, a number of shared theoretical inspirations—especially the work of Gilles Deleuze and Felix Guattari (2004, or. ed. 1980) and actor–network theory—mean that rhizomatic media ecology and SWF converge on some key methodological points. Sy Taffel (2019), in particular, has underlined the centrality of Deleuzian concepts of *rhizome*, describing the non-linearity of interrelationships between heterogeneous elements, and *assemblage* as:

A way of describing the process by which collective entities of humans, nonhuman biological organisms and nonliving actors (such as technologies) are composed. ... Thinking in terms of assemblages means going beyond isolated objects-in-themselves, instead studying the configurative relationships between entities. ... Things do not exist alone, or as connected individuals, but as entangled, intra-active assemblages. (p. 36)

For the purposes of this chapter, one of the most inspiring applications of this rhizomatic ecological approach regards narrative ecosystems. Addressing the specificities of recent media products, Guglielmo Pescatore (2018) has described the way that the new forms of storytelling adopted by these are not only transmedia but also made up of modular elements that cannot be regarded as ‘text-objects since their only narrative coherence constraints are local’¹ and ‘cannot be attributed to the strong intentionality of a subject governing the whole system’ but are rather designed around an initial ‘core set’ of ‘locations, characters, users and the properties deriving from them’ (p. 28). This core set constitutes the common ground for the interaction of a plurality of human and nonhuman actors and actants (i.e. authors, audiences, platforms and media formats) that translate it into a plurality of narrative orientations in reciprocal synergy or competition. It is thus not possible to make sense of these products by means of content or narrative analysis alone. What is required is a focus on the dynamic structuring of the environment promoting the interaction between actors and actants from which they stem. One of the most fascinating examples discussed by Pescatore (2018) are two experiments in *swarming storytelling* by Kai Pata (2011) in which users equipped with

¹ All translations of other languages are the author’s.

computers, cameras and smartphones were asked to produce bits of a story consisting of a picture and some comments. These collective endeavours, in which all participants acted as producers and audiences, generated hypertextual forms of storytelling characterised by the absence of a central text or ‘grand master’:

There are several access points to different stories. Users enter from the point that defines their perspective. Perspectives are individual, but different shared perspectives create niches, clusters of narratives and plots that generate greater engagement and are more commented upon, shared and fed by other writing processes. The system is polycentric, inhabited by narratives and [clusters] of stories ‘scattered’ across the ecosystem. (Bisoni et al., 2013, p. 20)

Clare Birchall and Peter Knight (2023) described the structure of the conspiracy theories that took shape and circulated on the Internet, especially during the COVID-19 pandemic and including those encapsulating refused knowledge about 5G, exactly in this way. This structure is described as a galaxy of modular bits of storytelling and pieces of knowledge lacking a grand master and accessible from several entry points—in which users were invited to ‘do [their] own research’ and ‘fill in the dots’ generating clusters of narratives of various degrees of persistence and intensity. This galaxy began to engage the Italian Stop 5G RKC and its arena during the COVID-19 pandemic. As Birchall and Knight (2023) underlined, ‘ecology provides a potentially productive way of thinking about the complex interaction between the content, the users, the technological infrastructure and the social dynamics of the different digital platforms’ (p. 53). From this perspective, the digital sphere can be seen as a vast interconnected discursive ecosystem (IDE), an environment in which different discourses and narratives can coexist and interact in multiple ways in their transmedia circulation, sometimes colliding and competing, sometimes adapting to each other and sometimes reassembling into new and broader ones.

Yet, the authors warn that the ecological metaphor ‘is not free of its own unspoken assumptions’ (p. 53). Within the current rhizomatic strand of research in media studies in particular, the metaphor tends to

drive scholars to overlook the concrete discursive production situations generating temporary, however stabilised, assemblages, in favour of a broad overview of the functioning of the ecosystem as a whole. In journalism studies, for example, Chris Anderson (2016) observes that these studies often take

‘a big data’ approach to analysing a large corpus of digital material. Fewer of them study journalistic diffusion in a more granular way, and almost none of these studies draw upon ethnographic or other forms of qualitative research in order to look at how these rhizomatic processes play out on the ground. (p. 420)

By contrast, the SWF always examines the system from one or more situated perspectives, focusing on ‘the situation of production [as well as on] how discourses are produced, by whom, with what resources, and under what conditions’ (Clarke 2005: 155), on the ‘[negotiations of] discourses in social relationships/interaction’, and on the ‘[production of] identities and subjectivities through discourse’ (Clarke, 2005, p. 155). We will therefore address the discursive knowledge production practices of the Stop 5G social world within the digital sphere as an interconnected discursive ecosystem ethnographically, with an analytical focus on the situatedness of their enactment.

5.3 Contesting 5G Deployment: From Scientific to Syncretic Patchwork Storytelling

As we have seen, in an ecological perspective, the structuring of RKC’s social worlds and of their wider arena, their forms of discursive production, their media-related practices and, ultimately, their shared beliefs are tightly intertwined: this means that transformation of one of these elements implies transformation in all the others too. From this perspective four phases in the Italian Stop 5G RKC can be distinguished:

- a public appeal phase (2017–2018, predating our empirical investigation) whose centre-stage players were groups of scientists contesting the official view of the effects of electromagnetic fields;
- an activist phase (2018–2020, that we observed ethnographically) in which a growing number of laypeople organised in local groups entered the social world and arena, publicly contesting the official view;
- an intermediate phase at the beginning of the pandemic crisis (February–April 2020) in which the RKC’s discursive practices began displaying significant transformation processes in an attempt to make sense of the virus;
- a subsequent pandemic crisis phase (until the end of 2020, when our systematic observation ended), in which a large part of the RKC took a populist (or even conspiratorial) turn.

As we saw above, this can also be read as a movement from a ‘scientific’ to a ‘syncretic’ patchwork storytelling approach in the RKC’s knowledge production practices. I will now move onto reconstructing the main stages in this turn by means of the tenets of the (media) ecological approach outlined above.

5.3.1 RKC as a Network of Independent Scientists: the Adoption of a Scientific Patchwork Storytelling Strategy (2017–2018)

In the first phase of challenge to 5G rollout, the Stop 5G RKC was largely made up of international ‘independent’ researcher groups (as the RKC defines scientists not funded by the industry) pursuing a strategy already used to challenge 3G and 4G technologies (Soneryd, 2007). On the basis of a growing number of articles published in peer-reviewed journals, they resorted to public appeals published in scientific journals and on the web to raise awareness in the institutions and public opinion on the non-thermal effects of non-ionising electromagnetic radiation. These effects were (and are) dismissed as scientifically unfounded by organisations such as the International Commission on Non-Ionizing Radiation

Protection (ICNIRP), an NGO tasked with defining safety guidelines for exposure to electromagnetic fields and recognised by the World Health Organisation. These guidelines—which consider the thermal effects alone—have been accepted by the EU and the US and set the limit at 61 V/m (Italy applies a more restrictive limit of 6 V/m).

In 2015, for example, several ‘scientists engaged in the study of the biological and health effects of non-ionising electromagnetic fields’ published an international appeal related to technologies preceding 5G. This urged ‘the United Nations (UN) and all member states in the world to encourage the World Health Organization (WHO) to exert strong leadership in fostering the development of more protective electromagnetic fields (EMF) guidelines’² than those put forward by the ICNIRP, which was accused of ignoring all scientific literature on ‘long-term exposure and low-intensity effects’. Two years later, in September 2017, Professors Rainer Nyberg and Lennart Hardell quoted this appeal in their *The 5G Appeal*,³ asking the EU to apply ‘a moratorium on the roll-out of 5G’. The appeal argued that the existence of low-intensity, long-term non-thermal effects had been proven by a vast amount of scientific literature, and predicted that these effects would be even more severe with 5G. Moreover, it explicitly accused the ICNIRP of a conflict of interest in its refusal to consider this body of knowledge, quoting an article written by Lennart Hardell (2017) himself, which called the ICNIRP an ‘industry loyal NGO’ in support of this. The appeal received two replies in that same year (Hardell & Nyberg, 2020) from the European Directorate-General of Health and Food Safety and from the European Commission which dismissed the low-intensity non-thermal effect hypothesis and rejected the conflict of interest allegations.⁴

² Scientists call for Protection from Non-Ionizing Electromagnetic Field Exposure, available at <https://emfscientist.org/index.php/emf-scientist-appeal>

³ The 5G Appeal, available at <http://www.5gappeal.eu/appeal>

⁴ The letter from the Directorate-General quotes ‘the Ombudsman conclusion in case 208/2015/PD5 concerning conflicts of interests in a Commission expert group on electromagnetic fields is that there was no maladministration by the European Commission’ (http://www.5gappeal.eu/wp-content/uploads/2018/06/reply_ryan.pdf).

That same year a number of Italian health- and science-related associations adopted this appeal strategy to put pressure on national and local government. This was especially the case of ISDE (International Society of Doctors for Environment) Italia which invoked the precautionary principle to demand a moratorium on 5G experimentation and an international appeal from ISDE International followed in 2018.

For their scientific claims, these and other appeals relied on literature reviews and meta-analyses produced by independent researchers throughout the history of the challenge to mobile communication infrastructure deployment. A case in point is the BioInitiative report (BIR),⁵ published online for the first time in 2007, reissued in extended form in 2013 and updated several times since then. This vast literature review constitutes one of the main references used by the RKC and its appeals. The report has been strongly criticised by several independent and governmental research groups for a plurality of reasons, however, ranging from poor selection criteria concerning the studies included in the review to conclusions that are only partially grounded in the review itself. On the occasion of the publication of the 2013 edition, for example, a critical assessment by *Science-Based Medicine*, an online editorial project on scientific controversies owned and operated by the *New England Skeptical Society* (an independent, non-profit organisation) reported several scientific flaws in the report and considered it an evident case of confirmation bias, or ‘cherry-picking’:

The authors of the BIR commit exactly this error with EMF bioeffects studies, by speculating at length about possible implications of studies reporting effects of EMF while saying little about studies that failed to find effects. Rather than taking a ‘weight-of-evidence approach’ to put all the studies together in a coherent picture, most authors simply listed numbers of studies reporting effects (of whatever nature at whatever exposure level) in comparison with those that found none. (*Foster & Trottier, 2013*)

⁵<https://bioinitiative.org/>

This discursive strategy—that I define ‘scientific patchwork storytelling’—consists of the RKC assembling its shared knowledge by collecting disparate ‘scientific’ sources all in support of the existence of non-thermal effects, where ‘scientific’ is understood as ‘published in peer-reviewed journals’, regardless of their reputation within the scientific community or of the reception of the individual articles in the existing literature. Moreover, these sources—dealing with different electromagnetic wave frequencies and reporting various types of biological effects—are neither assembled into a coherent picture nor consider studies reporting conflicting results, even solely for the purposes of deconstructing them.

In this strategy, conflicting studies are dealt with asymmetrically; to make sense of them, the RKC moves onto different epistemic ground and mobilises a narrative centred on the conflicts of interest of adversarial scientists and groups of experts. In particular, the newest studies are dismissed as uproar deliberately produced through industry-funded research to generate a state of uncertainty that fosters the survival of the status quo—and facilitates the deployment of the new 5G infrastructure. Historicisation is a key discursive strategy here: rather than engaging in deconstructing and criticising opposing studies, the RKC deploys historical comparison to make sense of the present situation. The slow recognition of tobacco’s carcinogenicity, in particular, is used as a probatory example of industries’ ability to deliberately manufacture scientific uncertainty (Bero, 2005; Brandt, 2012) and considered proof of the plausibility of an alleged ongoing disinformation campaign within the scientific community.

The adoption of this discursive strategy by the RKC must be viewed in the light of its objectives in the broader 5G deployment arena: these groups of scientists aim to draw institutional and public attention to what is regarded as a deliberately ignored body of scientific evidence. Yet scientific patchwork storytelling, together with its complementary delegitimising narrative, played a pivotal role in shaping RKC knowledge in the subsequent phase as well, when activists entered the scene and engaged in 5G opposition at the local and municipal levels.

5.3.2 The Activist Phase: Guarding the Borders of Scientific Patchwork Storytelling (2018–2020)

In September 2018 Arthur Firstenberg launched the international Stop 5G on Earth and in Space appeal,⁶ to the ‘UN, WHO, EU, Council of Europe and governments of all nations’ and signed by a number of ‘scientists, doctors, environmental organizations and citizens’. The appeal adopted the strategy employed by the RKC in its previous phase, with the issue of the deployment of the new communicative infrastructure being strictly framed as a health and environmental problem, and the appeal backed by a body of peer-reviewed articles proving the existence of non-thermal EMF effects. It accused public and private institutions of conflicts of interest in refusing to take these into account in policymaking. This time, however, the appeal did not come from groups of independent scientists but from civil society: Firstenberg is an American activist affected by electromagnetic hypersensitivity, a condition triggered by EMF that is not recognised by WHO. This new central importance of the activist scene added extra complexity to the RKC’s social world and marked a new phase in the opposition to 5G deployment.

An activist scene began to take shape in Italy this same year, when the 5G issue gained public visibility and was covered by legacy media, a process fostered by a plurality of events. The first of these was a sustained effort to promote public awareness by national associations and groups, such as Alleanza Italiana Stop 5G (AIS5G),⁷ an ‘informal committee and a non-partisan network ... standing up for the ... precautionary principle’ founded in 2018. This same year, to reach a wider audience than its blog and Facebook page followers, the committee launched a crowdfunding campaign and bought a national newspaper page in *Il Fatto Quotidiano* and some advertising space on the leftist radio station Radio Popolare. It also launched an awareness-raising campaign in various cities involved in 5G experimentation which relied on mobile billboards mounted on trucks, a communication strategy also used by no-vax groups and Pro

⁶International Appeal Stop 5G on Earth and in Space. Available at <https://www.5gspaceappeal.org/the-appeal/>

⁷<https://www.alleanzaitalianastop5g.it/442967936.html>

Vita associations. The committee's main promotor and spokesperson was (and still is) journalist Maurizio Martucci (see Chap. 4 by Paolo Bory), 'author of many investigative and crime books on soccer [who was now working] on health and environment, rare conditions and alternative medicine',⁸ and had just published a self-defence manual for electrosensitive people (Martucci, 2018), and later, in 2020 published *#Stop5G* (Martucci, 2020), a bitterly critical investigative book on 5G to which we will return. Those named by the committee's blog as affiliated and/or cooperating with the network were ISDE Italia, Associazione Nazionale Piccoli Comuni di Italia (Italian Association of Mayors of Small Towns), several influencers who have, elsewhere, been defined as 'catalysts of scientific dissent'⁹ (Bory et al., 2023) and Bologna's Istituto Ramazzini, a non-profit social cooperative operating in the field of independent research on cancer and medical science popularisation.

This institute was also at the heart of a second key event. Until 2018, the knowledge assembled by the RKC through scientific patchwork storytelling lacked a significant piece in its claims to public credibility. Although it included epidemiological and in vitro experimental evidence, and hypotheses on the biological plausibility of EMF effects, it lacked in vivo studies on a significant number of animals. This gap was filled by the findings of two studies published by independent researchers: one from the American National Toxicology Program (National Toxicology Program, 2018) and one from Istituto Ramazzini (Falcioni et al., 2018). Both reported the insurgence of specific kinds of cancers in mice and rats exposed to (non-5G) electromagnetic fields. Although part of the scientific community cast doubt on the soundness of these studies and the significance of their results (including ICNIRP¹⁰), this research gained attention from legacy media, including national public and private TV channels. A case in point is the journalistic TV programme *Report*, screened on national public channel RAI3, which broadcast an alarming

⁸ From his blog on *Il Fatto Quotidiano* (<https://www.ilfattoquotidiano.it/blog/mmartucci/>).

⁹ 'A public influencer who does not belong to the scientific community and contributes to the dissemination of science-related populist narratives within a grassroots ecosystem of resistance to institutional science' (Bory et al., 2023, p. 1).

¹⁰ See INCIRP (2018).

episode¹¹ on the possible effects of 5G. Links to the episode were published on the AIS5G blog and Facebook page and in other RKC ecosystem ‘owned spaces’¹² (Penttinen & Ciuchita, 2022), becoming a reference point for many groups of activists who contributed to disseminating it.

Finally, from 2018 onwards, the attention of legacy media and the RKC was also captured by a series of public statements from European Union bodies such as the Scientific Committee on Health, Environmental and Emerging Risks (SCHEER) which included 5G its list of 14 ‘emerging issues to bring to the attention of the Commission service’ because ‘the lack of clear evidence to inform the development of exposure guidelines to 5G technology [left] open the possibility of unintended biological consequences’ (SCHEER, 2018, p. 14)¹³; the document ‘5G Deployment: State of Play in Europe, USA and Asia’ (2019) commissioned by the European Parliament Committee on Industry, Research, and Energy stating that ‘significant concern [was] emerging over the possible impact on health and safety arising from potentially much higher exposure to radiofrequency electromagnetic radiation arising from 5G’; and the 2021 report *Health Impact of 5G*,¹⁴ commissioned to Dr Belpoggi by the European Parliament’s Panel for the Future of Science and Technology (STOA), that raised several concerns. These were supplemented by several court rulings reported with considerable emphasis by

¹¹ *Onda su Onda*, Rai3 26/11/2018.

¹² From our ethnographic observation, digital spaces through which members of RKC interact online can be classified in *owned spaces* (Penttinen & Ciuchita, 2022) under their direct control such as—in our case—the constellation of Stop 5G public local Facebook groups and the related private WhatsApp groups; *spaces of resonance* that are perceived as sympathetic, such as the WhatsApp and Telegram groups of the same name (The Walk of Change), whose focus is not exclusively 5G but which are bitterly critical of the scientific community; and *spaces of confrontation* that, on the contrary, are perceived as hostile, such as the online spaces of tech magazines like *Wired*. Moreover, we define *media territory* as the ensemble of media employed by the RKC to perform specific practices (Tosoni & Ciancia, 2017, p. 44; Tosoni & Turrini, *forthcoming*) such as online and offline activism practices. As we will see, the RKC’s discursive strategies, tones and rhetoric vary in these different spaces.

¹³ Later on the committee produced more reassuring statements on EMF. See, for example, https://health.ec.europa.eu/system/files/2020-04/citizens_emf_en_0.pdf: ‘there are no evident adverse health effects if exposure remains below the levels set by current standards’. Yet, some research results contradicting this were reported.

¹⁴ Available at [https://www.europarl.europa.eu/RegData/etudes/STUD/2021/690012/EPRS_STU\(2021\)690012_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/STUD/2021/690012/EPRS_STU(2021)690012_EN.pdf).

the local and national press which recognised some types of tumours occurring in cases of heavy work-related use of mobile phones as occupational accidents. Notably, in the first of these (2012), the Corte di Cassazione of Brescia was called upon to decide upon litigation between a manager and INAIL (the Italian occupational health institute). The court dealt with the contradictory scientific literature presented and decided to accord greater credit to studies produced by ‘independent researchers’, officially validating the delegitimising narrative that complemented the Stop 5G scientific patchwork storytelling strategy.¹⁵

The momentum of this rise in the visibility of the potential 5G risks led to the creation of two Italian groups on Facebook by the end of 2018, both of which adopted the title of Firstenberg’s appeal: Stop 5G Italia and Stop Sperimentazione 5G. The two groups soon amassed over 10,000 members each. Other groups followed, on both Facebook and WhatsApp, (e.g. No Elettrosmog) sometimes translocally addressing different categories of people (such as the Facebook group Mamme Stop 5G, for mothers). Concomitantly, a vast constellation of small local groups appeared in all the main Italian cities, all using the Stop 5G label. Most of these groups adopted a similar media territory¹⁶ for their activist practices centred around a Facebook group (e.g. Stop 5G Milano) for communication among members and sympathisers and a more restricted interactional space on WhatsApp for discussions and coordination between activists. These local groups organised their activities autonomously but were loosely and informally coordinated in national online groups, where they could also get in contact with national associations.

Local activist groups, national associations and committees adopted a twofold, synergic strategy. On one hand they engaged in awareness-raising campaigns consisting mostly of public conferences, leafleting, demonstrations and Facebook activities. In 2019 dozens of public conferences were held all over Italy organised not only by national associations and committees but also by local groups with the participation of one or more members of national associations and at which institutional

¹⁵ Full sentence in https://www.bollettinoadapt.it/wp-content/uploads/2017/05/20121015-snciv@sl0@a2012@n17438@rS.clean_.pdf

¹⁶ See note 12.

representatives were frequently invited to participate as speakers or attendees. These events were launched and advertised on the RKC's online owned spaces and reposted in its spaces of resonance. They were also often documented (sometimes via live streaming) to produce excerpts later published and circulated on the Internet.

On the other hand, while pursuing their strategy of appeals at the national and European levels, national associations and groups backed up local groups in pressuring local administrations and mayors directly, or indirectly through the mediation of local politicians (Gerli, 2021). In this phase, mayors' public health responsibilities meant that they were authorised to suspend 5G adoption. This battle was fought through on- and offline signature collections, meetings with the authorities, and, when needed, legal means. Here, the knowledge produced by scientific patchwork storytelling played a key role since the point was to convince mayors that there were sufficient scientific grounds to justify the precautionary principle. Local groups informally worked together to gain the scientific and legal expertise needed to generate effective dialogue with the authorities. They also received support from national groups. In this phase the main knowledge authorities for the RKC as a whole were, in fact, researchers at Istituto Ramazzini (with some local groups even organising visits to laboratories) and the AIE, both of whom helped local groups frame their instances and public discourse firmly within the limits of scientific patchwork storytelling. AIE president Dr Paolo Orio, for example, not only gave many public talks on EMFs but he also constantly monitored scientific databases for new peer-reviewed studies confirming the effects of non-ionising radiation. These articles were then posted, together with comments on their significance, on the AIE's owned space, in national and translocal Stop 5G online groups and other spaces of resonance, where they were intercepted, collected and reposted by local activists in their groups. At a local level, they were often collected and archived in external repositories like Google Drive as lists of links or a collection of PDF files that were then circulated among other groups, together with legal documentation and models of the letters to be written to mayors. These repositories and lists were also used to socialise new members to the knowledge shared by the RKC or to contradict the opposition in online discussions in spaces of confrontation. What was actually at stake here

was a fully fledged creation of a canon of symbolic resources assembled through scientific patchwork storytelling that came to summarise and stabilise the knowledge shared by the RKC as a whole.

This twofold strategy proved highly successful. In an article dated 16 July 2020,¹⁷ *Wired Italia* revealed that 431 mayors and local administrations (the number would grow to 600 in total out of around 8000 Italian municipalities) had halted the deployment of 5G on their territories. Whilst the pandemic crisis sped up this process, an in-depth study by Paolo Gerli (2021) on 5G municipal bans has shown that these moratoria were not related to COVID disinformation (as is often argued by legacy media) but were rather the result of painstaking perseverance by civil society, activists and local politicians that had begun long before. A significant role in this work was played by the capacity of a heterogeneous and decentralised network of activists to open a dialogue with public institutions, keeping its discourse within the limits of scientific patchwork storytelling and avoiding science-related populist stances (Mede & Schafer, 2020) or forms of conspiracism that would have delegitimised their demands.

This was the result of efforts to demarcate the boundaries of RKC discursive production made by its knowledge authorities and by national and local Facebook groups' administrators acting as gatekeepers. Administrators proved capable not only of defending their online spaces from unwanted intrusion by trolls and comments explicitly advocating acts of sabotage or vandalism against antennas, but also from posts on topics not strictly related to 5G (from chemical trails to vaccines) and from overly controversial sources of knowledge. The regulations of the Stop Sperimentazione 5G group, for example, explicitly stated:

Here quarrelling, rudeness, praising violence and inciting crime is strictly forbidden. Since our ideas vary, arguments on politics or topics other than [5G], such as vaccines, chemical trails and conspiracies, are also strictly forbidden. Before publishing an article, you are requested to verify the trustworthiness of its source. Do not publish articles or videos written or filmed by amateurs, or news that has not yet been verified; this will make

¹⁷ <https://www.wired.it/internet/tlc/2020/07/16/5g-comuni-italia-mappa/>

us look like flat-earther nut jobs to be mocked and easily dismissed. This is something that our negligence must not allow to happen. We must always be credible and well-informed. If you are not sure about some information, consult scientific data and laws before beginning a dialogue with institutions or scientifically trained people—we want them on our side.

Consequently, although several conspiracy theories regarding 5G were already circulating on the Italian web in 2018 and 2019 (for example, on the use of 5G technologies in a project for mind control called Monarch),¹⁸ they did not permeate the guarded borders of the Stop 5G social world.

Yet, there are two significant exceptions to this form of boundary work in this phase, both strictly centred on scientific patchwork storytelling and framing the deployment of 5G as a health- and environment-related issue, and both of which, as we will see, played a key role during the pandemic phases. The first was an alternative narrative promoted, in particular, by Martucci's AIS5G in its owned spaces (and then reposted in several spaces of resonance). In this narrative, 5G was framed not (only) as a health risk but as the linchpin in an already ongoing transhumanist transformation of society that promoted pervasive mediated communication and (allegedly) 5G-related technologies, like the Internet of Things, AI and virtual reality, as means of exploitation and social control. Indirectly rebutting the public praise by tech companies and the institutions of the social gains associated with 5G in what has been called a technological drama (Butot & van Zoonen, 2022), this narrative adopted a cultural criticism approach warning against the erosion of social ties, culture, critical thinking and, therefore, freedom that such a transhumanist turn implied. This narrative, that began to resonate in local groups' private and owned spaces, was fully developed in Martucci's (2020) book *#Stop5G* and, as will be seen, rose to prominence during the pandemic crisis.

The second exception was not a fully fledged narrative, but rather an epistemological stance generating a plurality of sub-narratives. It comprised a collective effort to mobilise the (scientific-patchworked) knowledge of the RKC to interpret phenomena observed daily by activists; for

¹⁸<https://disinformazione.it/2019/07/30/5g-monarch-preludio-al-nuovo-ordine-mentale/>

example, attributing personally experienced health symptoms and conditions to EMF, searching the urban landscape for new 5G antennas to monitor the deployment process (after learning to recognise them through pictures shared online), but also associating tree cutting to the scientifically based notion that trees are barriers to 5G millimetre waves. This led to formal demands for an end to tree cutting to local institutions and appeals. This epistemological stance broke the immediate connection between the RKC's shared knowledge and scientific sources prescribed by scientific patchwork storytelling and promoted by scientists as knowledge authorities: during a public conference held in Milan in 2019, for example, one of the convenors projected a video downloaded from the Internet showing dead birds, attributing the event to the activation of a 5G antenna.

As we will see, this epistemological stance, in synergy with the delegitimising narrative that complemented scientific patchwork storytelling, opened the door to a populist and, not infrequently, conspiratorial turn during the pandemic crisis.

5.3.3 Enter the Virus (February–April 2020)

The pandemic crisis marked a radical transformation in the structure of the RKC and its broader arena, media ecosystem and discursive practices. From a communicative point of view, these months registered a crack-down against the circulation of controversial COVID-19-related knowledge in the media. In April 2020, for example, AGCOM, the Italian Communications Regulatory Authority, began applying severe restrictions and cancelled several controversial TV programmes and channels. Concomitantly, all the main platforms enforced stricter content moderation policies, including demonetisation and deplatformisation. In this scenario, the virus was a key actant in the definition of the RKC discursive production situation and within its ecosystem and the primary work of local activist groups in physical spaces, such as conferences, weekly leafleting and signature collection, was suddenly suspended. This weakened the relevance of locally owned communication spaces used for coordination in favour of national and translocal online groups enjoying a

wider (and quickly increasing) audience: these groups soon became the centre of the activists' media territories.

COVID-19 took the limelight in discursive terms as well: participants were soon engaged in never-ending collective discussions seeking to make sense of the new situation. Encouraged by insistent (fake) news about the concurrence of 5G adoption in Wuhan and the outbreak of the epidemic (news that was also reposted by Gunter Pauli,¹⁹ economic advisor to the then-Italian President of the Council Giuseppe Conte, in a tweet that was interpreted by the activist groups as an authoritative confirmation), activists saw the ongoing pandemic crisis from the vantage point of their shared knowledge on EMF, adopting the epistemological stance already well established in the previous phase. Several authors have described speculation on the correlation between 5G and COVID-19 in conspiracy theory terms (Bruns et al., 2020; Gagliardone et al., 2021; Meese et al., 2020). Yet, this seems to apply only in cases promoting the nonexistence of the virus and its use by the authorities as a cover story to hide what was actually an upsurge in a severe 5G-induced electromagnetic condition, as was claimed by alternative medicine practitioner and antivaxer Thomas Cowan in a video that was widely circulated on Facebook before being removed. This hypothesis, whilst present in activists' discussions, was rejected as antiscientific by the majority of the RKC's members, who tended to explain the situation in terms of a population left more vulnerable to infection due to the effects of 5G electromagnetic radiation on the immune system.

This hypothesis was compatible with the canon of scientific literature collected by the RKC,²⁰ yet it was not directly addressed and supported by it. In this way, the epistemic line drawn by scientific patchwork storytelling began to be crossed, and this increased when the groups' participants started to find new knowledge authorities elsewhere as a basis for their claims. This was the case for catalysts of scientific dissent such as Claudio Messori (whose official channel ByoBlu was first demonetised

¹⁹'Science needs to demonstrate & explain cause & effect. However science first observes correlations: phenomena that are apparently associated. Let's apply science logic. Which was the 1st city in the world blanketed in 5G? Wuhan! Which is the 1st European 5G Region? Northern Italy' (3/22/2020). See <https://twitter.com/MyBlueEconomy/status/1241732814959149067>

²⁰See, for example, Johansson (2009).

and then shut down by YouTube in March 2021) and Rudolf Steiner, founder of anthroposophy and main reference point for Dr Cowan. In particular, Steiner was credited for attributing huge epidemic outbreaks to the progressive electrification of the planet. Meanwhile, group admins were struggling to exert their authority as gatekeepers and keeping discussions strictly focused on 5G- and EMF-related issues, resorting to public reprimands and content deletion, partly due to fears that a platform increasingly perceived as hostile might sanction or remove their online spaces.

5.3.4 The Populist Turn and the Adoption of Syncretic Patchwork Storytelling (The Remainder of 2020)

The most radical changes in the RKC's discursive knowledge construction practices were initiated precisely by an abrupt turnaround in online groups moderation. In late March-early April, the unrest caused by strict governmental virus containment policies, a shared perception of increasing control in legacy media and social platforms, and social alarm triggered by news of experimentation on a new class of SARS-CoV-2 vaccines convinced the admins of a growing number of local, translocal and national groups to cease filtering non-5G-related contents and even share this content themselves. When asked about a shift that led many groups to—in some cases, completely—shift their focus from 5G, activists answered that there were now more pressing issues at hand or that the 5G battle had to be seen as part of a much broader clash with technocapitalism.

While the narratives characterising the previous phase persisted, and scientific literature on the dangers of 5G was still posted, a plurality of themes coming from different sources was now being shared in the RKC's owned spaces in an attempt to make sense of a rapidly evolving situation. These themes ranged from new age spirituality and the beneficial effects of 7.83 Hz vibration (disrupted by EMF) to the relationship between facemasks and blood acidification (which exacerbated the dangerous effects of EMF and 5G), sociological warnings about the radicalisation of surveillance capitalism, dystopias revolving around supposedly

5G-enabled technologies like AI, virtual statements about the DNA-altering proprieties of new vaccines and considerations on the artificial nature of the virus.

Reports of ongoing censorship, content deletion and deplatformisation were also a significant component of the mix, leading users to adopt measures to circumvent algorithmic content moderation based on assumptions, or ‘folk theories’ (DeVito et al., 2017; Moran et al., 2022; Myers West, 2018), on how such algorithms work. Several groups were renamed, for example, to avoid automatic detection, and potentially troublesome keywords were encrypted (the word Vax was replaced by the word Cax, e.g.). The media territories of various groups were reconfigured through migration from WhatsApp to Telegram, which was considered ‘freer’ and more ‘secure’ (migration from Facebook to platforms like VK was often discussed but never really put in place). Interestingly, users also started to save cultural artefacts (like Dr Cowan’s videos) in external shared repositories like Google Drive to preserve them from deletion and share them with other users. This practice ultimately assembled a new eclectic canon of heterogeneous resources that replaced the old scientific literature-based canon.

The transformation of the discursive practices of a large part of the RKC was more radical, however, and cannot be described simply in terms of this new thematic eclecticism. Especially in bigger groups, collective discussion of posts shared was replaced with what might be called ‘flow communication’: users started constantly reposting links, videos, memes and other cultural artefacts from a heterogeneous variety of sources, selecting contents that captured their attention in spaces of resonance proposed to them by platform algorithms, or received directly from their contacts, including on WhatsApp. Content was now simply juxtaposed to other content, and links were not infrequently reposted and cross-posted many times by different, or even the same, users. This form of syncretic patchwork storytelling assumed forms closely resembling trans-media swarming storytelling, as described in Sect. 5.2. Rather than a collectively negotiated ‘grand master’ (see above, Sect. 5.2), groups hosted a considerable number of modular micronarratives, pieces of information, speculations and hypotheses, each constituting an ‘access point ... to different stories’ that users themselves assembled following links and

finding connections, with ‘shared perspectives [creating] clusters of narratives and plots that [generated] more engagement and [were] more commented [on]’ (Bisoni et al., 2013, p. 20).

Some narrative clusters in this vast interconnected discursive ecosystem replicated conspiracy theories, 5G-related and otherwise, as they have already been described by recent literature focusing on the pandemic crisis (Birchall & Knight, 2023; Fuchs, 2021), featuring depopulation plans, Big Pharma, the inoculation of 5G-operated microchips for mass control (or, alternatively, for population reduction), for example, and other hidden malevolent plans hatched by hidden powers. Other conspiracy theories, by contrast, were filtered out by RKC’s members’ ‘perspectives’. QAnon-related speculations, for example, never really took off within this communicative flow while they circulated in other Italian ecosystems, even encapsulating micronarratives on 5G (Murru, 2022).

Other narrative clusters, however, were associated with perspectives that leaned more towards scientific and political populism than conspiracy theories. This was the case, in particular, of the cultural criticism approach against transhumanism promoted by Martucci’s AIS5G, then coming to the fore. In this narrative, the economic elites, whose interests were naturally opposed to those of the common people, were acting with the complicity of the political health authorities to take advantage of the pandemic crisis and speed up the adoption of technologies leading to a future of radical exploitation, social engineering and erosion of freedom. This narrative became politically more radical, particularly after the government issued Decree-Law no. 78 of 16 July 2020, which deprived mayors of the power to suspend 5G adoption in their territories, initiating an institutional and legal battle with local government that is still going on. Backed by a significant part of the network of the ‘catalysts of scientific dissent’ and the Stop 5G RKC, Martucci spent the months which followed on denouncing an ongoing ‘electromagnetic coup d’etat’ and urging ‘the people’ to mobilise. Elsewhere (Bory et al., 2023), we have described how the hegemony of this overarching populist narrative and the adoption of a syncretic approach fostered the confluence of a part of the Stop 5G activist movement (the one closer to AIS5G) into R2020, a new political entity made up of various RKC’s connected via networks, and representing instances of this discontent.

Some of the groups that adopted the form of syncretic patchwork storytelling described above definitively moved away from a focus on 5G and EMF, de facto leaving the RKC; this was the case, for example, of the Italian WhatsApp group No Elettrosmog, which now mainly discusses vaccines, the Ukrainian crisis (with a prevalently pro-Putin stance), and issues featured in legacy media as their main agenda setters. Other groups, such as Stop 5G Italia, slowly regained their focus, and others never adopted the new discursive practice, such as the AIE online group, which stuck to scientific patchwork storytelling and its treatment of the 5G theme as a health and environmental issue. In so doing it regained its pre-pandemic knowledge authority role within the RKC, leading many groups back to their focus.

5.4 Conclusion

The purpose of this chapter has been to shed light on the co-constitutive relationship between RKCs as social worlds and their shared knowledge. To this end, I adopted an ecological approach to address the situatedness of the Stop 5G RKC discursive shared knowledge construction practices and the role played by the media, both legacy and digital, in these same practices. This required taking a non-media-centric approach to media (Morley, 2009) which sought to consider all the main heterogeneous elements tangled up in the RKC's discursive situations, thereby contributing to shaping its shared knowledge. Moreover, the adoption of a diachronic perspective was crucial to the attempt to clarify the process by which these can be de-stabilised and re-stabilised in new configurations with the inclusion of new entities, regarding which my focus was on the role played by SARS-CoV-2.

The case study in this chapter allows two orders of observation to be made. The first of these concerns the close interaction between the RKC's socio-structural and socio-symbolic levels. On one hand, specific organisational forms have proved highly significant to the enabling of specific shared knowledge production practices—contributing in this way to shaping the knowledge shared by the RKC. For example, in its activist phase—when a growing number of laypeople entered the social world,

drawn in by the growing visibility of the EMF issue in legacy media—the Stop 5G RKC was able to retain a stable discursive scientific patchwork storytelling practice, on the strength of an especially efficient organisational structure in both discursive gatekeeping and new members socialisation terms. As we have seen, this structure consisted of a network of informal local activist groups and a few national associations—many of which were under the leadership of those with scientific backgrounds or expertise, such as ISDE or AIE—mediating collaboration with independent scientists. On the other hand, transformations at the socio-symbolic level proved highly significant in fostering some forms of structural reorganisation. During the pandemic crisis, for example, the adoption of an unprecedented scientific populism in the 5G strategy and a syncretic approach to knowledge production paved the way for the convergence of a large part of the RKC in the broader political entity, R2020. At the same time, this also threatened to disrupt the RKC, causing several groups to lose their focus on 5G-related issues.

The second order of observations regards the role played by the media, both legacy and social, in the heterogeneous entanglements of the situations of discursive production. This is still an understudied topic, as a large part of the literature on the mediated circulation of knowledge refused by the scientific community focuses on the effects of users' exposure to fake scientific news and scientific misinformation (as these controversial pieces of information are more commonly and less symmetrically referred to within media studies) addressed using a behaviouralist 'powerful media effects' approach (Tosoni, 2021). As our case study shows, three main inextricably intertwined digital media roles can be identified in this RKC's production and circulation of refused knowledge: its role as an interactional infrastructure, as a vast interconnected repository of contents and symbolic resources (IDE, interconnected discursive ecosystem), and as a fully fledged player in the RKC's arena.

Regarding the role of (digital) media as interactional infrastructure, it should be noted that the RKC assembles specific and recurring media ensembles with which to perform its discursive practices (what we have defined as 'media territories'). For example, the media territories of local activist groups are structured in private WhatsApp groups and owned Facebook groups complementing offline meetings by hosting shared

knowledge production discursive practices. What is significant about this is not only the multi-sited (Marcus, 1995) nature of the RKC's discursive practices but also how a shift in these same discursive practices entails a reconfiguration of their media territories, as the RKC's turn from scientific to syncretic patchwork storytelling shows. Moreover, it can be observed that the RKC's members share a sort of 'symbolic map' of their media ecosystem, distinguishing their owned spaces into private and public, and non-owned spaces into friendly ('spaces of resonance') and hostile ('spaces of confrontation') and members' discursive practices may thus vary accordingly. We have seen, for example, how it was in private and resonance spaces that activists drew on the RKC's shared knowledge to make scientifically unfounded interpretations of everyday phenomena heard about on the Internet, such as ascribing a substantial number of bird deaths and tree cutting to 5G adoption.

Regarding the role of the media as a vast interconnected repository of symbolic resources (IDE, interconnected discursive ecosystem), the RKC's members actively searched the Internet for cultural artefacts conveying these resources, and came into contact with them through re-posts by other users acting as grassroots intermediaries (Jenkins et al., 2013) or via the intermediation of platforms' algorithms. It should be noted, however, that the distinction between media as repositories and media as interactional infrastructure is not clear-cut. In particular, the RKC's members adapted their content production to the narratives of other players in the same arena, engaging them in a sort of mediated indirect interaction. Vivien Butot & Liesbet van Zoonen (2022), for example, drew on Bryan Pfaffenberger's (1992) concept of 'technological drama' to describe the interplay between 5G discourses enacted by 'design constituencies' (e.g. the European Commission, tech companies and other public and private entities) and "impact constituencies' who [organised] on Facebook to oppose ... 5G' (Butot & van Zoonen 2022, p. 1). This drama was staged via 'news media as ambivalent intermediaries' and 'in front of audiences who [became] part of the scene' (p. 6). In our case study, we observed this form of indirect interaction during the pandemic crisis when the cultural critique approach to 5G opposition became dominant. Addressing the situatedness of the RKC's discursive production of

shared beliefs, therefore, means considering the symbolic resources available to it, as well as their complex interaction.

Finally, the RKC's members viewed legacy media and social media platforms as fully fledged players in their arena, by and large with an adversarial role. In particular, in a reversal of the trend by which the Internet is represented as a free speech space (and juxtaposed to state-controlled legacy media), mainstream platforms such as Facebook and YouTube began increasingly to be perceived as hostile after they tightened their content moderation policies during the pandemic crisis. Notably, these perceptions contributed to shaping the RKC's current discursive production practices (and therefore its shared knowledge), probably to a greater extent than the platforms' direct interventions—e.g. labelling some content as unverified or deleting it outright. As several authors have noted (DeVito et al., 2017; Moran et al., 2022; Myers West, 2018), people engaging with controversial content drew upon their previous experiences and observations to develop folk theories on the functioning of moderation algorithms in the platforms they employed, adapting their online behaviour to circumvent gatekeeping. In our case study, we saw, for example, that during the pandemic members of the RKC archived cultural artefacts that they considered at risk of automatic cancellation in online repositories which eventually canonised some of the narratives assembled through syncretic patchwork storytelling.

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6

Disentangling Discursive Spaces of Knowledge Refused by Science: An Analysis of the Epistemic Structures in the Narratives Repertoires on Health During the Covid-19 Pandemic

Ilenia Picardi, Luca Serafini, and Marco Serino

6.1 Introduction

Epistemic positioning matters in defining the social worlds that build knowledge claims. As Chap. 1 argued, the research project of which this study forms part labels its object of study *refused knowledge* (RK), taking into account the positioning of science, which situates RK claims outside the boundaries of knowledge corpora that it considers legitimate. Consistent with the symmetric perspective of STS, this chapter aims to understand how refused knowledge communities (RKC)s position science with respect to their knowledge claims, to comprehend if these social worlds refuse the science that denies them validity or adopt strategies designed to enrol science—i.e. scientific knowledge's claims,

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technoscientific devices, scientists' institutions, scientists and scientific papers. To this end, we will enquire into the meaning-making processes regarding health within social worlds made up of people who, within RKC, work with shared objects to legitimise their knowledge claims. The hypothesis of this work is that knowledge can be analysed as a discursive assemblage made up of both *knowledge claims* and *heterogeneous actors* enrolled to legitimise this knowledge. We have therefore enquired into the association processes via which RKC enrol claims and actors *within their discursive universes* and, thus, the ways in which they build meanings and attribute credibility to knowledge about health. As we shall see, a particular kind of enrolment process concerns how science is recruited by RKC in legitimising the knowledge they build.

The methodology chosen is based on quantitative and qualitative procedures combined in a nested research design. More specifically, ours is a narrative approach (Czarniawska, 2004) integrated with the methodological framework of social network analysis (SNA; Wasserman & Faust, 1994; Scott, 2000). This set of techniques allowed us to visualise and analyse the relational properties of knowledge assemblages shared by RKC, thus uncovering the structures of discursive configurations that build, maintain and legitimise these forms of knowledge. Finally, analysing the narrative repertoires shared in different discursive configurations permitted us to identify the primary narrative structures within the RKC's discursive universes.

The analysis focuses on the online discourses shared in the Alkaline Water (AW) and Five Biological Laws (5BLs) RKC from January 2020 to December 2021 during a time span characterised by the emergence of the Covid-19 pandemic and the management of the related health crisis. Health issues gained prominence during the pandemic not only for RKC but also in society as a whole. Our interest in these social worlds was motivated by the fact that RKC developed a corpus of knowledge on health and wellbeing which is refused by scientific institutions, but without refusing institutional science. This peculiarity makes such RKC of interest in the study of the ways in which they incorporate science into their discourses.

This chapter is organised as follows. The next section focuses on concepts borrowed from the theory of social worlds and employed them in the network analysis performed in our study. Section 6.3 describes the

methodology and empirical material used in this study. This section clarifies the use of SNA in the context of the theoretical framework of social worlds, considering the use of SNA in Science and Technology Studies (STS), which has been the subject of much debate. Section 6.4 focuses on describing the analysis and its main results. Finally, the last section focuses on discussion and conclusions.

6.2 Analysing Spaces of Epistemic Enrolment Within RK Social Worlds

To understand how, within their discourse universes, RKC's enrol diverse claims and actors to legitimise their knowledge, we will borrow a number of key concepts from the social worlds' perspective. According to Clarke and Star (2008), the social world framework focuses on meaning-making processes within groups of actors 'doing things together' (Becker, 1986) and working with shared objects. Here, the focus is not on the 'doing' but on the linguistic utterances as part of the discursive construction of such objects, which can also be pieces of knowledge and play a central role in our analysis. It is around these objects that knowledge claims are built and conveyed in these social worlds. Our main reference is thus to the definition of social worlds as *universes of discourse* (Strauss, 1978), namely shared discursive spaces that are profoundly relational in nature, which prompted us to adopt a narrative approach (Czarniawska, 2004) to enquire into the most significant forms of narratives used by RKC's to legitimise and thus stabilise the knowledge they perceive as being refused by science and mainstream world views.

To identify the configurations on which RK relies, we opted for an approach derived from the *sociology of associations* (Callon, 1984; Latour, 2005) designed to trace the connections between knowledge claims and heterogeneous actors enrolled within these discursive worlds to support those claims. Analysing knowledge as an assemblage of claims and actors underlines the profoundly relational nature of knowledge itself and understands the latter's sharing within a community as one of the main

factors attributing it the status of knowledge, regardless of the truthfulness or falsity of its contents (Bloor, 1976).

Claims of knowledge are defined here as the cognitive elements considered true within a social world and constituting segments of its corpus of shared knowledge. The *epistemic enrolment space* is the set of discursive structures that guide, focus and delimit RK credibility attribution processes by assembling and re-assembling epistemic, social and political structures. In the case studies considered here, epistemic enrolment space analysis focuses on the discursive texture built by RKC's *entrepreneurs* (Clarke & Star, 2008), namely individuals, or groups of individuals, who are deeply committed to, and active in, promoting RK in online spaces within the social worlds observed.

In accordance with the social worlds' perspective, we will also examine the role played in these discursive universes by *implicated actors*, i.e. 'actors silenced or only discursively present—constructed by others for their own purposes' (Clarke & Star, 2008, p. 119). As discursively constructed primarily by RKC entrepreneurs to sustain RK, implicated actors are neither actively involved in negotiating self-representation in social worlds nor considered for what they say, write and argue; yet they can play a determinant role in enrolment processes into forms of knowledge. Finally, we will consider how both human and non-human actors are mobilised in the making up of epistemic configurations and thus we use the term *actors* to refer to both human and non-human actors.

Hence, within the epistemic enrolment space we will investigate knowledge claims concerning health as it is maintained by RKC, along with the networks of enrolment and counter-enrolment (Callon & Law, 1982) built to affirm this knowledge. The elements assembled in such networks were identified via web-ethnography during our research to enable us to explore RKC narratives as proxies to the *re-assembling of the social* (Latour, 2005), i.e. as a way to grasp how the various narratives bring heterogeneous elements together and into meaningful wholes (Czarniawska, 2004). The narratives constructed by RKC entrepreneurs contribute to sustaining wider *narrative structures* through which meanings and their relation to social worlds can be built and shared. Diverse sets of actors are enrolled into these narrative structures, to support and entangle the discourse universes deemed significant by RKC. Moreover,

in these discursive structures, our interest was identifying the objects (claims and actors) coexisting in the diverse structures making up the epistemic enrolment space and building narratives centred on a range of repertoires. Our analysis will focus on *boundary objects* (Star & Griesemer, 1989), nodes in the narrative structure network where various social worlds meet in arenas of mutual concern. Our interest in these objects was based on the key role they play within the translation processes (re)constructing meanings to meet the specific needs or demands of the various social worlds involved (Star, 1989).

6.3 Methodology and Data

Our analysis used a mixed methods perspective by combining the narrative approach (Czarniawska, 2004), designed to identify the discursive structures of the social worlds, and SNA.¹ This methodological strategy was chosen with a view to examining the relational structures at play in the enrolment of the various types of actors supporting RK claims within RKC's online discursive spaces and the narrative structures that inform the epistemic enrolment space of these social worlds. The stages in our analysis are shown in Fig. 6.1. As the entire data collection and analytical process dealt with qualitative data and prioritised the interpretation and analysis of texts and network graphs over formalisation, we consider our work to be concerned with qualitative networks (Bellotti, 2014; Hollstein, 2011).

In the first step in this research, from January 2020 to December 2021, our research group conducted web-ethnography on AW and 5BLs RKC's online spaces (blogs, Facebook pages and profiles, YouTube channels and the like) (Chap. 1). Using content analysis tools (Lieblich et al., 1998), we analysed the diaries resulting from this web-ethnography and, through an iterative coding and recoding process, we identified: (a) the health-related claims constituting the core of the corpus of refused

¹The tools of SNA are invaluable to a proper analysis of such worlds. They allow us to identify structures that would not otherwise be apparent and to measure important properties of those structures in a precise and reliable manner' (Crossley, 2010, p. 31).

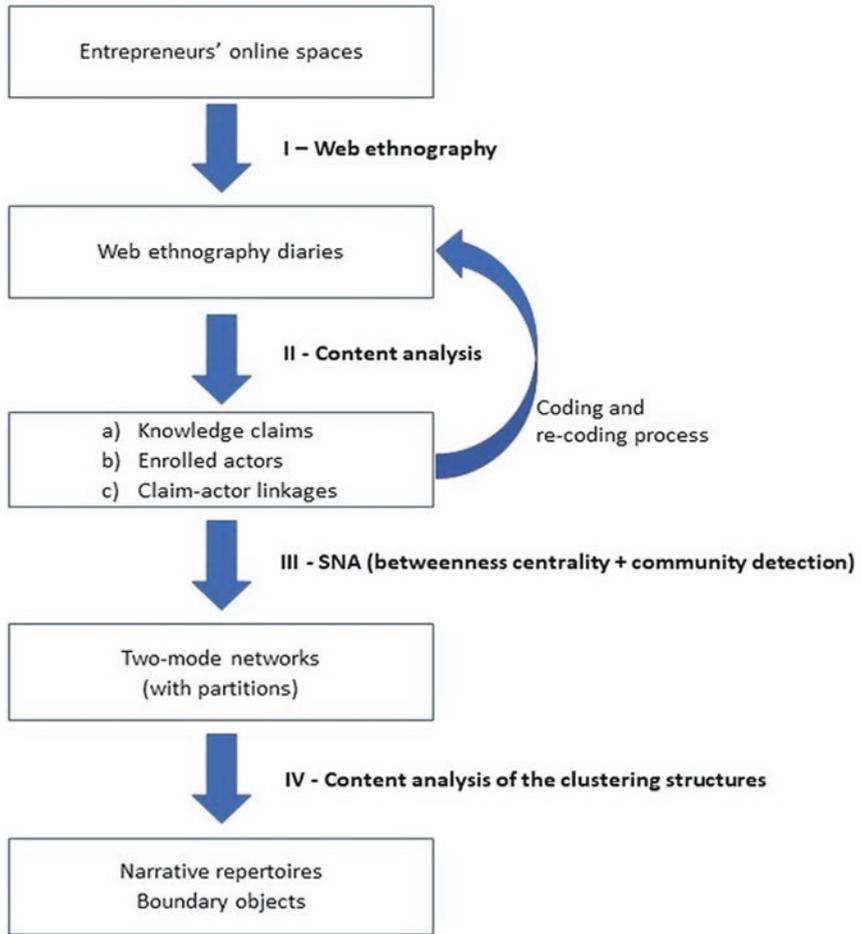


Fig. 6.1 Analytical process in each case study

knowledge;² (b) the enrolled actors interacting in the discursive universes (including implicated actors); (c) the linkages between claims and enrolled actors.

²Each claim is constructed by elaborating from the diaries' content (including observer's notes, utterances, and audiovisual material) the corresponding discursive unit, whereas the actors are extracted by selecting those enrolled to sustain the claims within the discursive content as a whole.

The three entity classes were translated into the elements constituting the two-mode networks discussed below. We also considered *mimicry practices* to be one of the strategies pursued by RKC's to give epistemic legitimacy to an RK corpus and depict it as an attribute of claim–actor linkages (see Chap. 1). Of the four enrolment strategies identified by the project, we chose to focus only on mimicry because of its significance in RKC's attempts to enrol in science. Performing mimicry strategies—from the simplest reference (either textual or visual) to technoscientific devices, e.g. a microscope or an oxidation-reduction potential (ORP) metre to more sophisticated biological elements and processes, e.g. extracellular pH, tumour micro-environment or T cell apoptosis—means borrowing science's constitutive 'marks' of scientific authority, including scientific institutions, scientists and scientific papers. The third step formalised the connections between claims and actors through two-mode networks, which proved to be useful in operationalising linkages between heterogeneous actors (Mützel, 2009)³ and emerged as appropriate to the kind of relational structure we intended to analyse. In fact, in two-mode networks, ties are allowed only between nodes belonging to two distinct node sets, as is the case with claims (Set 1) connected to actors (Set 2). These two-mode networks permitted us to visually explore the way claims are connected to actors, and thus the way actors aggregate around narratives expressed by claims. The analytical strategy we pursued therefore implied that actor–actor connections are mediated by the claims they jointly support whilst, conversely, claims are connected to each other insofar as they are sustained by the same enrolled actors—which is precisely one of the main features of two-mode (affiliation) networks, i.e. their *duality* (Breiger, 1974).

Adopting Actor Network Theory's perspective (Latour, 2005) led us to consider the associations between these elements as *social* in that such networks constitute a representation of social worlds as assemblages of heterogeneous actors and claims at work in discursive enrolment. As far as actor heterogeneity is concerned, it is well known that two-mode affiliation networks can help scholars produce 'heterogeneous maps', but do

³ See Contractor et al. (2011) for an example of a two-mode, multi-relational human–technology network. In STS, two key examples of such studies are Cambrosio et al. (2004) and Callon (2006).

not allow distinctions between the nodes or ties comprised in a single ‘mode’, which is considered a limitation (Cambrosio et al., 2004; Mützel, 2009, p. 874, 878; Venturini et al., 2019, p. 515). There is no doubt that, in our analysis, heterogeneous associations coalesce into a single set of linkages—whilst paying attention to the diverse strategies pursued to sustain claims through actors’ enrolment (see below)—but the differences between types of actors are retained as a node attribute (see Sect. 6.4).

Our network graphs were drawn up using *Gephi 0.9.7* software which we also used to obtain network statistics. We made use of a *force-directed layout* named *ForceAtlas2* (Jacomy et al., 2014) to spatialise networks and thus exploit the potential of visual network analysis (Venturini et al., 2021). As a basic centrality measure, we considered betweenness centrality for two-mode networks (Faust, 1997; Brandes, 2001; Everett & Borgatti, 2005). Notably, betweenness centrality expresses the potential for a node to act as broker or intermediary in a network (Scott, 2000, p. 86), which means a claim or actor connects different areas of the graph. In addition, we performed a community detection analysis using the Louvain modularity algorithm implemented in *Gephi* (Blondel et al., 2008). Each cluster (or *modularity class*) emerging from this analysis combined densely connected claims and actors.⁴ As far as the *mimicry* strategy was concerned, we highlighted this in the network graph by tie colour (see below).

Lastly, we qualitatively analysed the narratives assembled in each clustering structure by assigning a given repertoire to each of them, where this repertoire was the result of a further content analysis of the ensemble of claims and actors making up the clusters.⁵ This also enabled us to detect several sub-structures within these networks, namely different

⁴ However, the inclusion of actors within a given cluster may not be completely consistent with the main theme of the cluster: this is due to the probability of inclusion of a node within one cluster or another depending on the algorithm’s potential to yield ‘good’ partitions. After all, the ‘community structure of networks is, for instance, notoriously ambiguous’ and ‘for many networks, very different partitions are equally valid’ (Venturini et al., 2021, p. 9). In addition, the different clusters emerged as linked by inter-partition ties that often break their separation, which is a key feature of RKC network structures (and, in turn, represents one of the complexities of community detection).

⁵ Note that we will avoid speaking of communities in relation to the results of community detection procedure and refer to clusters or partitions (or modularity classes) instead, to prevent confusion with the term ‘community’ in the RKC sense.

sub-worlds each of which can be made of distinct clusters or even a combination of different clusters. This last step drew on the qualitative side of our analysis to interpret the betweenness centrality scores: when a high betweenness score expresses a 'flexibility' of objects in connecting diverse sub-groups of nodes that relate to it for different purposes, these objects (claims or actors) can be regarded as boundary objects that 'inhabit several intersecting social worlds' (Star & Griesemer, 1989, p. 393).

Finally, we analysed the network obtained from a union between the two social world networks examined. This analysis allowed us to identify the crucial statements and actors present in both RKC, thus understanding which Covid-19 pandemic period actors and statements helped legitimise the construction and dissemination of forms of RK and which discursive structures were activated within these social worlds to provide epistemic credibility to these forms of knowledge.

6.4 Analysis

The content analysis of the entrepreneur actors' discursive universes performed in the first step of the study provided two sets of claims (192 for the AW RKC; 365 for the 5BLs RKC) and actors (1939 for AW RKC, 1940 for 5BLs RKC) which, as a whole, constitute the 'dual' health-related knowledge cores of each of these universes. By enrolling these actors and setting forth these claims, entrepreneurs handle the knowledge cores assembled to build and legitimise RKC's claims. We identified various categories of enrolled actors, such as (1) organs, tissues and cells; (2) diseases; (3) polluting pathogens; (4) scientific disciplines; (5) distinguished international scientific scholars; (6) authors of scientific papers; (7) public figures active in the debate on Covid-19; (8) media and social networks; (9) scientific journals; (10) scientific institutions; (11) people who participate in chats (e.g. with comments) on the online spaces run by the entrepreneurs and (12) other concerned actors (e.g. children, the elderly and shopkeepers).

Following the steps outlined in the previous section, we translated these knowledge cores regarding health into networked form by focusing on the links between each claim and the various actors, which were in

Table 6.1 Number of nodes in the networks built for the two RKC and their unions

Node type	Alkaline water RKC		Five biological laws RKC		AW RKC \cup 5BLs RKC	
	Whole graph	3 <i>k</i> -core	Whole graph	3 <i>k</i> -core	Whole graph	3 <i>k</i> -core
Claims	192	126	365	292	550	428
Actors	1939	371	1940	715	3740	1082

turn connected to other claims. The assemblage as a whole thus resulted in a complex configuration of network nodes constituting one possible representation of these RKC and provided a map of their shared knowledge.

Indeed, a first examination of the networks analysed revealed a degree of complexity that hindered their readability due to excessive relational data ‘noise’. In other words, using these networks as maps required moving upward from a poorly informative terrain in which claims and actors may be associated with a minimum of one or two nodes (actors or claims, respectively) to a richer analytical framework in which associations involve at least three units for each claim or actor. We therefore focused analysis on a sub-network of each RKC extracted through a degree-based procedure called *k*-cores⁶ (Seidman, 1983) and then chose to limit our analysis to a subgraph with $k = 3$, that is, a 3*k*-core (Scott, 2000, p. 110; see Table 6.1).

For both RKC, the community detection algorithm generated a clusterisation of claims and actors. This was the first main finding in our analysis, i.e. that the discursive spaces depicted via SNA were organised around various narrative repertoires that could be seen in the clusters resulting from modularity analysis. The structures observed rendered the heterogeneity of assemblages and highlighted the differential associations revolving around knowledge-specific cores represented by the repertoires characterising the clusters. We thus analysed the structural configuration of claims and actors emerging from modularity analysis and identified

⁶‘A *k*-core is a maximal subgraph in which each point is adjacent to at least *k* other points: all the points within the *k*-core have a degree greater than or equal to *k*. [...] A *k*-core, then, is an area of relatively high cohesion within the whole graph’ (Scott, 2000, pp. 110–111).

the main repertoire within each cluster. Indeed, the clustering of the discursive universes showed not only that RKC use a range of repertoires but also that such repertoires adopt enrolled actor types that are specific to them. For instance, Cluster 5 in the AW RKC (see below) was concerned with cancer and chronic disease prevention through an alkaline diet and its actors included two scientific institutions, namely the *American Association for Cancer Research* and the *American Society for Biochemistry and Molecular Biology*, along with two papers (published in the journal *Cancer Research*), tumour cells and metabolic processes.

The node colours in the graphs shown below for the two RKC and their combination denote modularity class. Edge colours denote the presence (black) or absence (grey) of a mimicry strategy. A caption in each figure shows modularity class number and colour, plus the percentage (in parentheses) of nodes included in each class.

6.4.1 The Structure of Discursive Universes Legitimising RK Within the Alkaline Water RKC

Figure 6.2 illustrates the clustering structure of the claim–actor network within the AW RKC (modularity = 0.645). The content analysis of the claims showed a high degree of homogeneity of repertoires in each cluster, consequently different partitions can be classified as belonging to the narrative repertoires shown in Table 6.2.

By visually analysing the network, we detected some central clusters (i.e. those with modularity classes 8-9-6-4-0-1-2-3) and some peripheral ones (modularity classes 5-10-7). As far as the related narratives are concerned, Clusters 8-9-6—those mostly scattered across the core of the network—provided the primary repertoires used by RKC members to sustain alkaline water’s and food’s ability to purify the body and defend it against the effects of toxic and carcinogenic pathogens, including the power of the alkaline lifestyle to enhance the immune system. Note also that clusters 9-6 (which are identically labelled) refer to the same repertoire, although they are distinct in the modularity analysis because of their different network connection patterns. As far as actors are concerned, biomolecular actors prevail in Cluster 9, while Cluster 6 includes

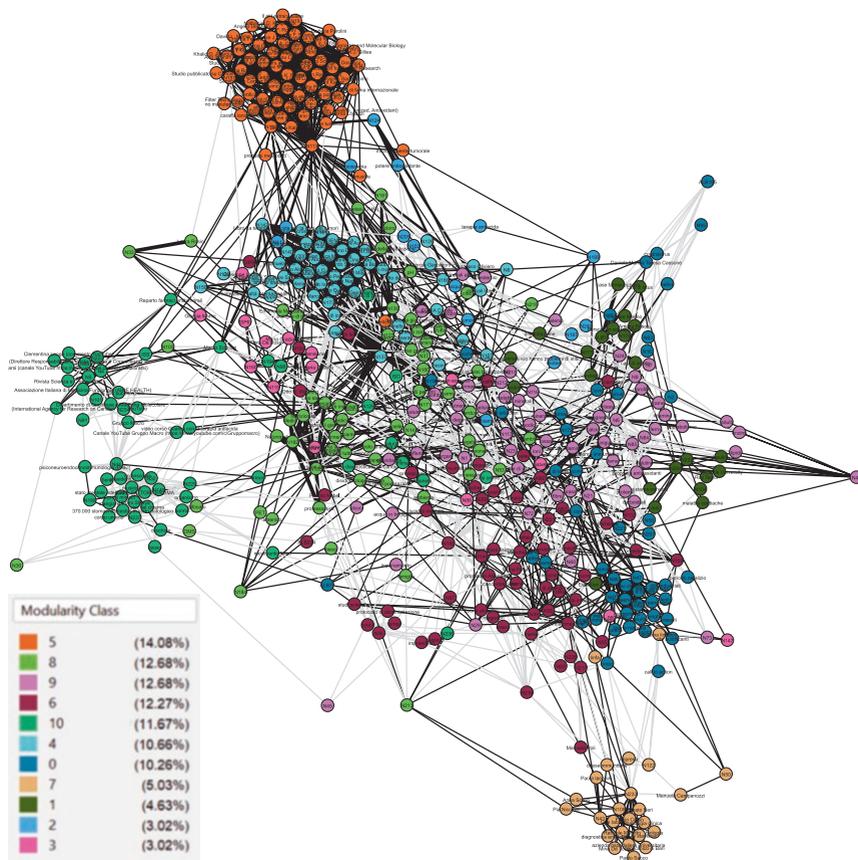


Fig. 6.2 Two-mode network of claims and enrolled actors: the case of AW RKC (black lines = mimicy strategy)

actors better fitting the highly energetic lifestyle idea. Both Clusters 9 and 6—along with Cluster 3—encompassed claims asserting that water and alkaline nutrition improve physical and mental performance, stimulate fertility, are beneficial during pregnancy and counteract inflammation caused by acidosis of tissues responsible for serious diseases and tumours. In the central Clusters 4 and 0, the promotion of water and alkaline food as a healthy lifestyle focused on different repertoires: acid–base balance as a characterising element for a healthy body and as an anti-ageing factor

Table 6.2 Clusters and related narrative repertoires within the AW RKC

Modularity class	Narrative repertoire
5	Alkaline water and food as a way of preventing tumours and chronic diseases.
8	The purifying effect of alkaline water and food capable of counteracting the effects of toxic and carcinogenic pathogens present in ordinary water and food. The alkaline lifestyle is seen as a way of preventing disease and reinforcing the immune system.
9	Water and food as ways to cleanse the body by eliminating acidity from it, improve health and mind/body performance and prevent disease.
6	Water and food as ways to cleanse the body by eliminating acidity from it, improve health and mind/body performance and prevent disease.
10	Modern medicine is not capable of understanding and getting rid of disease as it does not consider the mind–body relationship.
4	Acid–base balance as a key feature of bodily health and its anti-ageing effects.
0	Alkaline water and diet are a cure against viruses (including SARS-CoV-2) and opposition to governments' health policies to combat the dissemination of the virus.
7	Alkaline water to improve physical performance and strengthen the immune system.
1	Cure as a route to personal awareness.
2	Conflict with science's approach to the treatment of tumours, chronic diseases and Covid-19.
3	Health benefits of alkaline water.

(Cluster 4); alkaline water and diet as a defence against viruses, including the SARS-CoV-2 coronavirus (Cluster 0). The latter cluster includes claims contesting government anti-Covid-19 health policies. Cluster 1 is strongly connected to Cluster 0 and presents alkaline treatment as a way of enhancing personal awareness. Cluster 2 is less pervasive in the graph but still significant in its focus on claims arguing against the scientific approach to cancer, chronic diseases and Covid-19 treatment.

Another area is made up of peripheral Clusters 5-10-7. The Cluster 5 repertoire focused on alkaline water and food's ability to prevent cancer and chronic disease. Although claims relating to causes of tumours and their treatment were distributed across all clusters, this one featured

claim–actor relationships seeming to favour the enrolment of scientific actors in arguments for alkaline water as a way of preventing and treating tumours, such as scientific journal articles, their authors or tumour physiology subjects. In addition, science also plays an important part in the Cluster 10 repertoire although, in this case, it is not enrolled to legitimise the AW RKC corpus of knowledge but rather falls into this repertoire for its perceived inability to understand and treat diseases, given its failure to consider the mind–body relationship. Cluster 7 includes claims arguing for the use of alkaline water to improve physical performance and strengthen the immune system, mainly on the basis of actors in the biology and physiology spheres, as well as scientific institutions or physicians.

Tables 6.3 and 6.4 show the claims and actors with the highest betweenness centrality values. We noted that although both SARS-CoV-2 and Covid-19 are present in alkaline RKC narratives and feature in Cluster 0-2 repertoires, they do not play a key bridging role in them—either as a component in the claims or as actors. The narratives revolve

Table 6.3 Betweenness centrality of claims in the AW RKC network

Claim code	Claim	Betweenness centrality
N113	Acidosis causes chronic diseases.	0.149
N137	Alkaline water has an anti-ageing effect.	0.146
N125	Alkaline water cures human, animal, plant and the planet's health.	0.070
N157	Alkaline water prevents tumour formation.	0.066
N112	Acidosis causes tumours.	0.056
N145	Alkaline water enhances physical performance.	0.056
N185	Bottled water is harmful to health.	0.050
N182	Tap water is harmful to health.	0.049
N233	An alkaline lymphatic system enhances energy and concentration.	0.041
N6	Alkalinity reinforces improved organ function.	0.037
N44	The human body is an integrated and interconnected organism.	0.034
N47	Sick people have a capacity for self-recovery.	0.033
N127	Alkaline water cleanses organisms.	0.029
N86	Illness is caused by the accumulation of scum.	0.029
N87	Illness is a manifestation of the body's self-recovery process.	0.029

Table 6.4 Betweenness centrality of actors in the AW RKC

Enrolled actor	Betweenness centrality
RK publisher	0.062
Ionisers	0.055
Inflammation	0.037
Mind	0.037
Tumours	0.032
Energy	0.032
Joint pain	0.030
Sugars	0.027
Plastic bottles	0.024
The elderly	0.023
Medicines	0.022
Headache	0.020
Mental clarity	0.019
Italian Higher Institute of Health (Istituto Superiore di Sanità)	0.019
Alkaline minerals	0.018

mainly around associations between acidic and alkaline body conditions and their consequences. In this sense, claim N113 ('Acidosis causes chronic diseases') bridged Cluster 5 and the rest of the network by focusing on chronic diseases as a consequence of acidity, while claim N137 ('Alkaline water has an anti-ageing effect') lay mainly in a central position, arguing for the anti-ageing effects of alkaline water, i.e. a less extreme assertion that helps explain this location in the network. The following are the three most central actors: (1) publishers, because of their ability to provide RK with a readership; (2) ionisers, for their chief role as 'flexible' technological devices—as they serve various needs and have a range of possible uses and purposes (drinking, cleaning, saving money, avoiding plastic, etc.); (3) inflammation, as a widespread condition impacting health and wellbeing with various degrees of severity. Finally, the ties in the network denote the widespread use of mimicry practices (64.6% of the ties) to legitimise RKC entrepreneurs' knowledge claims. Here, mimicry also goes along with the enrolment of scientific and institutional sphere actors. Exceptions to the prevalence of mimicry are provided in Cluster 10, visibly peripheral and related to criticisms of institutional

medicine, and in other more central areas of the network, mostly involving Clusters 9-6-0, where the strategy is partly mixed.

Finally, we noted that the analysis highlights not only the significant role in holding different narrative repertoires together played by ‘tumour’ enrolment but also by knowledge claims relating to the use of alkaline water to prevent tumours and ‘acidosis’ (combated by the alkaline diet) as a cause of tumours.

6.4.2 The Structure of Discursive Universes Legitimising RK Within the Five Biological Laws RKC

The 5BLs RKC network would seem to be more complex than AW (Fig. 6.3). Basically, both the network and its $3k$ -core partition are larger than the other cases (see Table 6.1). This is due to (1) the higher level of interaction observed in the relevant online spaces, also evidenced by a large number of online users coded as actors, and (2) the wider spectrum of the knowledge contents coded as claims. As in the former case, the networked 5BLs RKC was divided up into different areas identified using the modularity algorithm. Its community structure (modularity = 0.762) was rather fragmented with the algorithm yielding 17 modularity classes. Similar to AW, these clusters form both a core area (bottom centre of the graph) and a number of peripheral areas, plus several clusters occupying less dense areas and with sparser distribution than the others.

Starting from partitions with the largest proportion of nodes, Cluster 7, with its ‘Causes of disease: fear and psycho-social conflicts’ repertoire, is located bottom left in the graph and divided up into two parts, one of which is highly cohesive and peripheral while the other is sparser and closer to the core of the graph. The two parts of Cluster 7 are mainly held together by one of the claims with the highest betweenness in this graph, namely CLB186 (‘Fear of death causes pneumonia’), which is representative of the repertoire of this cluster and also one of the claims relating health narratives to the Covid-19 crisis. Interestingly, the connection between this claim and the right half of the cluster is based on strategies other than mimicry: the separation, then, concerns the way this claim’s

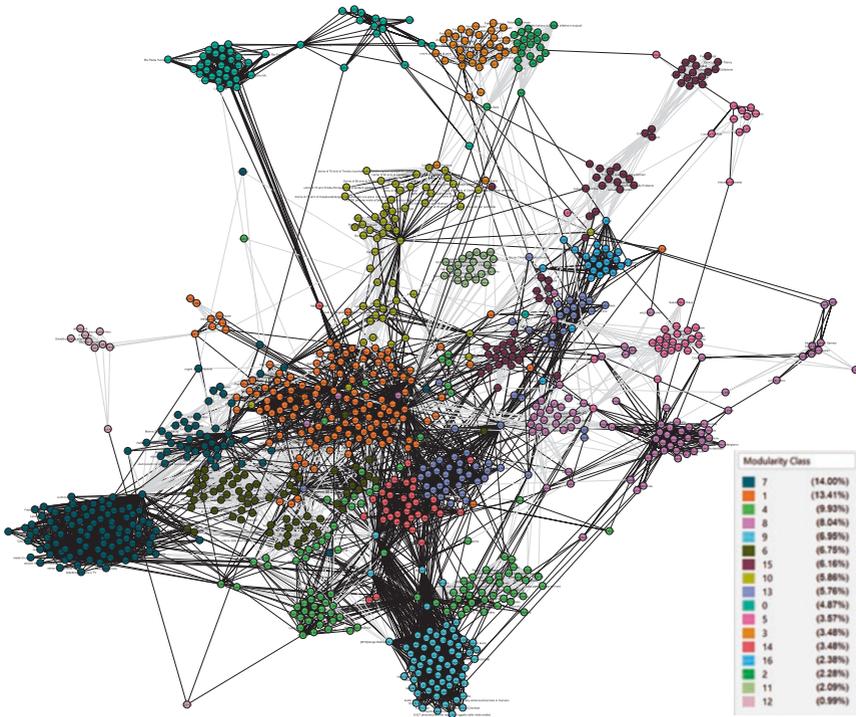


Fig. 6.3 Two-mode network of claims and enrolled actors: the case of 5BL

narrative is oriented towards enrolled actors, which form two seemingly unrelated sub-groups⁷ joined up by a ‘boundary claim’—which owes its role to its connection to actors from other clusters (Table 6.5).

Cluster 1’s repertoire relates to Covid-19 counter-narratives and occupies a central position in the graph, with some ramifications towards other nearby areas. This cluster comprises the two central claims CLB84 (‘Covid-19 is no more harmful than seasonal flu’) and CLB80 (‘Mortality rates from Covid-19 are very low’, see Table 6.6), both of which are related to denying the dangers of Covid-19 (Table 6.7). These two claims

⁷In actual fact, setting the modularity procedure’s ‘resolution’ parameter to less than 1—to produce a larger number of modularity classes (Blondel et al., 2008)—yields a clustering in which the two sub-parts of Cluster 7 belong to different clusters. By default, all the analysis presented was performed with a resolution set on 1.

Table 6.5 Clustering of narrative repertoires within the 5BLs RKC

Cluster	Narrative repertoire
7	Causes of disease: fear and psycho-social conflicts.
1	Covid-19 counter-narratives.
4	Viruses not harmful to health.
8	Functioning of biological laws.
9	Hamer medicine vs institutional medicine.
6	Links between institutional medicine, economic interests and policies.
15	Pandemic as a social experiment vs self-determination in health matters.
10	Causes of disease: diagnostics and prevention measures.
13	Epistemic relativism on Covid-19 and health.
0	Functioning of biological conflicts.
5	Causes of disease: childhood trauma and inner conflict.
3	'Warmongering' and violent science.
14	Unreliability of experts and institutions.
16	Opacity of health institutions.
2	Technocratic and hyper-interventionist medicine for economic interests.
11	Media terrorism.
12	Enslavement of the psyche.

are responsible, to a considerable extent, for Cluster 1's central position because of their connections with nodes from other clusters—notably often related to people who comment on content online (one of which has the highest betweenness of all the actors). Cluster 4's location (bottom of the graph) in the network is also a subtle one. The narrative repertoire of this cluster is about denying the dangers of viruses in general. It is split up into two sub-partitions, plus other sparse nodes. The two-halves of the cluster are kept connected by the highly central CLB134 claim, which states that 'The virus is not dangerous'. In sum, the positions of the first three clusters reflect the way in which the Covid-19-related repertoire tends to spread across the RKC, albeit in different forms.

A further set of repertoires belongs to clusters intersecting with the above. This is the case of Cluster 6 ('Links between institutional medicine, economic interests and policies'), Cluster 13 ('Epistemic relativism on Covid-19 and health') and Cluster 14 ('Unreliability of experts and institutions'), which lie at the core of the graph, though with some ramifications. This is a set of repertoires that more directly question the

Table 6.6 Betweenness centrality of claims for the 5BLs RKC network

Claim code	Claim	Betweenness centrality
CLB84	Covid-19 is no more harmful than seasonal flu.	0.093
CLB478	Social distancing brings about health-related and social damage.	0.082
CLB186	Fear of death causes pneumonia.	0.080
CLB80	Mortality rates from Covid-19 are very low.	0.070
CLB289	Seasonal flu is more dangerous to health than Covid-19.	0.069
CLB134	The virus is not dangerous.	0.066
CLB492	The media provide epidemiological data which is not to be trusted.	0.049
CLB262	Restrictions such as quarantine and isolation are of no use in combating the spread of Covid-19.	0.045
CLB475	Asymptomatic patients are not affected by Covid-19.	0.032
CLB483	Approval procedures for the Covid-19 vaccine are neither transparent nor reliable.	0.028
CLB224	Avoiding restrictions is of use in reducing the effects of Covid-19.	0.028
CLB169	Molecular medicine neglects the processes by which diseases originate.	0.020
CLB197	The psyche is the underlying origin of disease-related processes.	0.020
CLB204	The real world is made up of intangible factors impacting health.	0.020
CLB28	Systemic reality impacts health.	0.020

Table 6.7 Betweenness centrality of enrolled actors for the 5BLs RKC network

Enrolled actor	Betweenness centrality
Children	0.0545
Symptoms	0.0444
Parents	0.0393
Physicians	0.0252
WHO	0.0205
La Stampa (Italian newspaper)	0.0168

validity and legitimacy of science and medicine. Furthermore, Cluster 13 is split into two-halves joined by the central CLB478 claim ('Social distancing brings about health-related and social damage'—see right-hand side of the graph), and the upper-right branch of this cluster extends to

another area where Cluster 16 ('Opacity of health institutions') and topics more closely related to 5BLs and the latter's interpretation of conflict and trauma (Clusters 8 and 5) are located.

Hence, Covid-19 and health institution narratives are scattered across the RKC and intersect one another, especially those related to clusters with more ties towards the core of the network than towards its edges. In this respect, Clusters 5-8-9-0 are located along the periphery. These denote narrative repertoires specific to the 5BLs and are thus more extreme than other narratives, such as more Covid-19 and related counter-narrative focused ones. As far as the presence of mimicry as a strategy is concerned, the graph shows not only how prevalent this is (67% of all ties) but also how it flows through several branches of the network, following traces of Covid-19 pandemic counter-narratives and criticisms of medicine and science. In this respect, the way Cluster 15 ('Pandemic as a social experiment vs self-determination in health matters') is positioned merits consideration. This partition's subsets are detached from one another, denoting a presence within the core of the graph, along with more 'relaxed' narrative repertoires, and also towards the periphery (upper-right-hand side)—hence with more extreme subjects (such as totalitarianisms or 'quantum field theory'). The extreme sub-partitions also differ in strategy; the nodes in the upper branch of Cluster 15 are bound together by linkages unrelated to mimicry, while the opposite is true of the lower branch. Finally, this strategy also characterises the peripheral cluster ties related to 5BLs specific repertoires.

6.4.3 Combining the Network Structures of the Two RKC

The network combining the two RKC (Fig. 6.4) is modular in structure (modularity = 0.762) with a complex appearance in that it at least partly parallels the two distinct RKC groupings but also, at the same time, reveals some merging between the AW and 5BLs RKC repertoires. The clustering results shown in Table 6.8 indicate that several clusters share the same repertoire and relate to claims from one of the two social worlds or to their combinations. The repertoires of the two RKC tend to

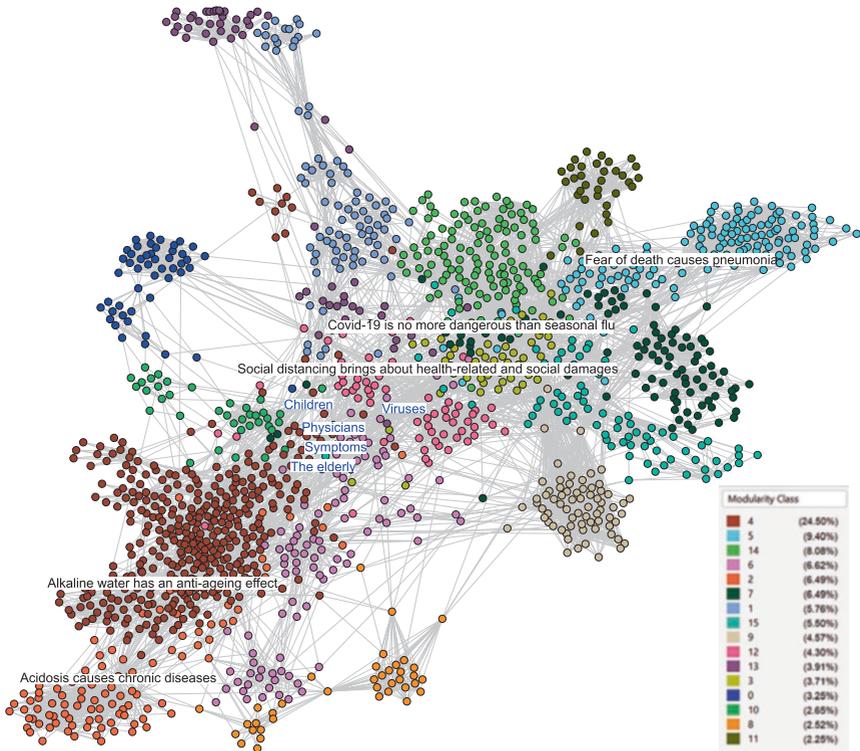


Fig. 6.4 Two-mode network of claims and enrolled actors obtained by joining the AW and 5BLs RKC

preserve their specificity. The 5BLs RKC focuses on criticisms of the way governments and health institutions have managed the pandemic (modularity Classes 13–14), general criticism of institutional medicine along with the denial of the Covid-19 pandemic (modularity Classes 1-7-8-12-15, even though Clusters 7 and 8 include a minimum of alkaline RKC claims) and 5BLs' interpretation of the psychological and social causes of the pandemic and the damaging effects of social distancing and protection devices (links to a counter-narrative on vaccines, Clusters 0-3-5). Clusters 2 and 4 are related to the AW RKC repertoires; namely, the acidity-alkalinity dichotomy and the beneficial effects of food and water for health and wellbeing (the latter with a minimum of claims from

Table 6.8 Clustering of narrative repertoires within the network obtained by joining the AW and 5BLs RKC

Modularity class	Narrative repertoire 1	Narrative repertoire 2	Claim origin
13	Pandemic management criticisms (1).		5BLs
14	Pandemic management criticisms (2).	5BLs vs institutional medicine.	5BLs
0	Damaging effects of face masks and distancing from the 5BLs point of view.		5BLs
1	Criticism of scientific and health institutions, the pharmaceutical industry and related communications.	Healthcare despotism.	5BLs
5	Fear and psycho-social factors as causes of disease and the dissemination of Covid-19.		5BLs
4	Alkaline water and food as sources of health and wellbeing.	Criticism of the conventional vision of healthcare and disease.	Prevalently alkaline
6	Individuals' internal conflicts, body reactions and holistic view of organisms.		5BLs/ Alkaline
11	Awareness.		5BLs
9	5BLs subject matter (generic).	Criticism of science from the 5BLs point of view.	5BLs
7	Criticism of institutional medicine (1).	Denial of Covid-19 pandemic (1).	Prevalently 5BLs
8	Criticism of institutional medicine (2).		Prevalently 5BLs
12	Criticism of institutional medicine (3).	Denial of Covid-19 pandemic (2).	5BLs
10	Symptoms and malaise as a reaction to past trauma.		5BLs
2	Alkaline vs acidic condition and tumours.		Alkaline
3	Criticism of the Covid-19 vaccine and vaccines in general.		5BLs
15	Criticism of prevention and medical intervention.	Denial of Covid-19 pandemic (3).	5BLs

Table 6.9 Betweenness centrality of claims for the joint AW and 5BLs RKC network

Claim code	Claim content	Betweenness centrality	Modularity class
CLB186	Fear of death causes pneumonia.	0.074	5
CLB84	Covid-19 is no more dangerous than seasonal flu.	0.073	14
N137	Alkaline water has an anti-ageing effect.	0.060	4
CLB478	Social distancing causes health-related and social damage.	0.056	3
N113	Acidosis causes chronic diseases.	0.053	2
ALB195	Governments and the media spread fake news about the pandemic along with false epidemiological data.	0.049	14
CLB80	Mortality rates for Covid-19 are very low.	0.042	14
CLB289	Seasonal flu is more dangerous to health than Covid-19.	0.041	15
CLB134	The virus is not dangerous.	0.036	7
CLB262	Restrictions such as quarantine and isolation are of no use in combating the dissemination of Covid-19.	0.031	15
ALB13	Personal protective equipment and technologies promoted by the institutions to combat the spread of Covid-19, such as gloves and face masks, and vaccines, are harmful and dangerous.	0.030	0
N125	Alkaline water cures human, animal, plant and the planet's health.	0.029	4
N145	Alkaline water enhances physical performance.	0.028	4
N185	Bottled water is harmful to health.	0.027	4
CLB492	The media provide epidemiological data which cannot be trusted.	0.024	14

the 5BLs RKC). Cluster 6 is the only truly mixed one in terms of the origins of its claims.

Despite this apparent segmentation, the two RKCs seem to interact in some way, particularly if we look at the claims and enrolled actors with the highest betweenness centrality scores (Tables 6.9 and 6.10). The graph in Fig. 6.4 shows the labels of the nodes with the highest scores for

Table 6.10 Betweenness centrality of claims for the joint alkaline and 5BLs SW network

Actor	Betweenness centrality	Modularity class
Children	0.073	10
Physicians	0.050	12
Viruses	0.035	13
The elderly	0.023	4
Symptoms	0.021	10
Medicines	0.019	6
Inflammation	0.019	4
Researchers	0.018	4
Vaccines	0.018	5
Tissues	0.018	6
WHO	0.017	8

betweenness only. As far as the claims are concerned, the first five sorted by betweenness score lie on the upper (5BLs) and lower (AW) sides of the graph and concern, respectively, Covid-19-related narratives and those regarding acidic/alkaline polarities in relation to health; this also means that the network is virtually divided up into these two RKC.⁸

As far as the five enrolled actors (*children, physicians, viruses, the elderly* and *symptoms*) with the highest betweenness score are concerned, it is noteworthy that these are the actors that truly connect the two-halves of the graph and, more generally, the two different RKC in them. Topologically, they are also exactly central in the graph, and when their connections are observed in detail, they link claims from both social worlds. More importantly, these actors can be considered boundary objects for their potential to translate interests from the different RKC.

⁸ Another claim—not shown in the graph—comes from both these two RKC and is explicitly coded as such: ALB195 ('Governments and the media spread fake news about the pandemic along with false epidemiological data'). Nonetheless, it is the only such claim in a cluster made up entirely of 5BLs RKC claims.

6.5 Discussion and Conclusions: Disassembling and Re-assembling Science

This chapter presented an enquiry into the epistemic structures constituting the AW and 5BLs RKC, in an attempt to discover (1) the core RK claims concerning health within the discursive universes in which they are constructed and disseminated, (2) enrolment by advocates of RK and (3) how entrepreneurial actors position their claims vis-à-vis science. In this respect, the choice to pursue a combination of qualitative analysis and network analysis techniques is in line with the chapter's aim to study RKC as social worlds and map their organisation as assemblages among claims and heterogeneous actors. The aim of the chapter's modularity analysis was to cast light on the structure of these social worlds and make them more understandable. This analysis provides the reader with an overview of the associations that emerged as significant in their support for RK, but with an eye to how entrepreneurial actors enrol other heterogeneous actors.

Thus, the clustering of the online discursive universes examined showed not only that entrepreneurial actors use differentiated repertoires but also that these repertoires rely on specific types of enrolled actors. The configuration of the assemblages involving claims and actors relates to RKC's shared purposes and practices, however the latter are internally differentiated. Thus, one or more clusters may comprise elements whose association emanates from a given 'commitment' regarding health (e.g. alkaline water as a cure, symptoms as psychic-bodily reactions, etc.). This commitment is highlighted as the analysis displays the different repertoires constituting the knowledge core represented by the clusters obtained through community detection. In this respect, this analysis revealed that knowledge about health as it is practised within social worlds may be constituted through commitment to, and participation in, one or more RKC, leading to broader arenas made up of multiple worlds organised ecologically around issues of mutual concern and commitment to action (Clarke & Star, 2008; Shibutani, 1955; Strauss, 1959). What is of chief interest in the configuration of the RKC examined here is that

discursive enrolment occurs with a deployment of different actors functioning as allies irrespective of their origin, usage or function.

Thus, the analysis showed the *hybrid nature of the RKC epistemic enrolment space*. Reticular representation of the discursive universes of entrepreneurial actors who play a leading role in RK legitimisation processes allowed us to analyse the way such RK is supported by networks constructed by assembling actors and claims from different RKC. In the transposition from one social world to another, the roles and interests of actors and claims change. These latter, as elements in assemblages, are arranged and aligned to respond to the cognitive needs defined in the various clusters identified in the analysis, but without being forced to conform entirely to the different local settings in which they are enrolled.

In this regard, observing the science transposition processes, which are enrolled in various forms in an attempt to support the legitimisation of RK, is particularly significant. In the discursive universes designed to increase RK credibility, ongoing processes involving moving closer to and further away from science were observable. Within the RKC's epistemic enrolment space, the enrolment of science emerges as the result of a continuous (re)negotiation of science *contestation* processes, on one hand, and science *purification* processes, on the other. These two trends emerged from our analysis as follows.

The narrative repertoires marshalled to contest science revolve around the *medicine betrayed* theme. Having abandoned a holistic vision of treatment that conceives of wellbeing as an expression of an integrated mind–body organism and the medical profession's ethical principles as set out in the Hippocratic Oath, modern medicine is unable to understand the causes of diseases. Institutional medicine focuses on treatment of disease rather than healthcare. In science-critique narratives, a key role is played by interpretations of cancer treatment and the practices pursued to limit the dissemination of Covid-19. Both the scientific community and communication structures are enrolled in these narratives as organisations manipulated by lobbies which include denying scientific claims, thus providing alternative claims to explain health problems. The methods and tools of institutional medicine (including diagnostic ones) are rejected, as they focus on disease rather than health and on a conceptualisation of the body as a set of distinct organs, including the mind, rather

than the unitary organism propounded by holistic models. Epidemiological data is denied, i.e. deemed untrustworthy on the grounds of institutional medicine's distorted perspectives or corruption in the scientific community and information systems. Finally, official views of the causes of disease are considered to be wrong. In the case of the AW RKC, diseases are attributable to a state of acidosis in the body's tissues, while in that of 5BLs, they are to be explained by conflicts bound up with past psychic traumas leaving biomolecular scars in human tissues.

Thus, for these RKC's health is a matter of rebuilding a state of lost equilibrium. In the AW RKC, the equilibrium referred to is the acid–base equilibrium. Displacement from this balance causes cellular ageing, inflammation, malaise, chronic and/or degenerative diseases and tumours. Alkaline water is thus considered capable of restoring this balance, and a wellbeing and prevention practice as well as a treatment for diseases and tumours. The body of knowledge advocated by the 5BLs, on the other hand, refers to a body–mind balance. Diseases are, in fact, interpreted as imbalances generated by psychic conflicts deriving from prenatal and natal traumas. Care practices within this narrative infrastructure are presented as paths of awareness requiring subjects' active agency. And it is essentially through this process of acquiring—strongly practical and experiential—scientific knowledge that science is purified. Science itself is enrolled to legitimise forms of RK, e.g. the biomolecular claims attesting to the benefits of alkaline water on health or the scientific evidence marshalled to testify to the veracity of Hamer's psychobiological framework model.

These disassembling and re-assembling science processes are driven by a constant reworking of claims and actors within the RKC epistemic enrolment space. A key role in these processes is played by the boundary objects identified in the analysis of the unions between the two RKC's. The merging of the repertoires belonging to the two RKC's highlights claims and enrolled actors acting as boundary objects in the narratives examined. What counts in this respect is the role played by these boundary objects in the processes of *translation* between different repertoires: indeed, these objects allow us to move from, say, a biomolecular repertoire to a political repertoire—as happens, for e.g. with viruses, a recombinant agent in these repertoires. Narrative structures are also sustained by these translations.

Within this heterogeneous epistemic enrolment space, the tension deriving from these science disassembling and re-assembling processes is balanced by boundary objects responding to the need for network coherence. Paradoxically, our analysis showed that a key role in holding different social worlds together is played by actors such as *children, physicians, viruses, the elderly* and *symptoms*, together contributing to reinforcing a narrative on health entirely played out within the contested narratives of these RKC.

In this sense, a key role is played by Covid-19, which acts as an arena within these social worlds and allows further elements designed to augment RK credibility to be added. The SARS-CoV-2 virus, infection, Covid-19 symptoms, social distancing and the health-related and social damage it causes, pandemic fake news allegations and the epidemiological death and infection figures spread by governments and the media are all enrolled to bring together elements from different social worlds (among these, the social worlds of science) to further legitimise the forms of knowledge advocated. In this sense, an analysis of RKC focusing on the assemblages at work within these discursive spaces can increase our understanding of the extent to which RK is the result of bricolage processes and a reworking of conceptions and practices which acquire meaning in relation to one another, even when the pieces of knowledge thus deployed and articulated come from science itself and are reframed and recombined, as needed, to make sense of these assemblages.

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7

Challenging the Institutional Politics of Life in the Making of Refused Knowledge

Stefano Crabu 

7.1 Introduction

Addressing the question of how people actually give credibility to health-related refused knowledge (RK) inevitably involves taking on the challenge inherent in considering fundamental issues concerning their epistemic stance and beliefs about the social and political organisation of science and of biomedicine-related fields. Indeed, refused knowledge communities (RKC) can be analytically framed as specific social worlds (see Chap. 2 by Federico Neresini), in the context of which questioning science-related epistemic, professional, and political arrangements is a crucial dimension of mutual concern. Hence, understanding refused knowledge followers' attitudes to biomedical theories and their part in public health and healthcare systems and professional healthcare practice is urgent if we are to cast light on the conditions nurturing the legitimacy of knowledge emerging outside the boundaries of science.

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Against this backdrop, the aim of this chapter is to shed light on how RKC engage in a contentious relationship with the conditions under which biomedical knowledge is shaped and mobilised by health professionals. In so doing, it elucidates how these contentious dynamics are entangled with the ways in which RKC confer credibility and reliability on refused knowledge itself. Indeed, RKC are not merely concerned with challenging the content of scientific and biomedical knowledge. They also question its epistemic, professional, and economic roots, that is, RKC argue that claims and knowledge elaborated and enacted in the context of biomedicine, and the life sciences in general, are enmeshed with specific social, political, and material interests, and therefore either not to be believed or at least treated with scepticism. Hence, not only does conferring credibility on refused knowledge imply certain assumptions about trust and truth but it also requires critical scrutiny of what we might call ‘the institutional politics of life’ (see Rose, 2007)—that is, how States and related governmental bodies, medical agencies, life scientists, and health professionals control, manage, and reshape the very vital capacities of human beings as living bodies.

Critical scrutiny of this sort is generally performed by a number of pivotal actors widely recognised by refused knowledge followers as epistemic experts and public spokespersons (Bory et al., 2022) due to their book and paper publishing work, management of relevant digital spaces (such as blogs, public Facebook pages, Telegram, YouTube, and TV channels), and organising of in situ initiatives (such as conferences, workshops, and learning events), also designed to recruit potential new followers. These actors thus undertake claim-making (Lindekilde, 2022), acting both as gatekeepers of truth in relation to a refused knowledge corpus, and as ‘analysts’ considered capable of uncovering political and economic dimensions allegedly capable of jeopardising scientists’ integrity and trustworthiness and that of their knowledge and healthcare practice. Thus, RKC claim-makers articulate demands centred on the interests of a single social world or capable of bearing on a number of social worlds constituting an arena ‘organized ecologically around issues of mutual concern and commitment to action’ (Clarke & Star, 2008, p. 113; see also Chap. 8 by Morsello et al.). Moreover,

considering that the claim-making process ‘includes two actors—a subject (claimant) and an object (addressee)—and a verbal or physical action (demanding, protesting, criticizing, blaming, etc.)’ (Lindekilde, 2013, p. 1), RKC claim-makers often have explicit and formalised epistemic concerns regarding biomedicine. Hence, they make socio-political demands for a different (public) health and illness management in the public sphere. In fact, in their attempts to publicly demonstrate the relevance of adopting a given refused model of healing and caring for the sake of individuals and society at large, claim-makers generally adopt an adversarial relationship to scientific communities and medical practitioners. In so doing, not only do they critically address specific scientific health- and illness-related contents (e.g. the safety of vaccines, the effectiveness of chemotherapy, and the non-danger of electromagnetic waves), but they also target the epistemic, professional, and political conditions by which biomedical knowledge is shaped (e.g. alliances between scientific institutions and the biomedical industries) and enacted by healthcare professionals.

From these starting premises, this chapter aims to analyse the ways in which the most influential claim-makers of the four RKC considered in this book (see Chap. 1 of this volume) seek to challenge the current politics of life as a way of enhancing the refused knowledge credibility conferral process. This focus on the claim-makers’ perspective allows us to highlight how RKC critics discuss the epistemic conventions, rationalities, policies, and professional arrangements underpinning the institutional politics of life in their approach to health- and illness-related issues. Hence, in the process of legitimising a body, or pieces, of refused knowledge, claim-makers elaborate specific substantive concerns regarding the epistemic, economic, and political background of biomedical knowledge and professional healthcare practice. In this regard, certain arguments inherent to the politics of life critique are specific to a single RKC (e.g. how to practically manage a state of malaise), while others cut across multiple social worlds (e.g. global biotech corporations as a threat to public health), thus generating a shared discursive arena.

7.2 Contesting Contemporary Politics of Life in the Legitimation of Refused Knowledge

Since World War II, scientific biomedicine has succeeded in establishing its epistemic authority and moral force in the public understanding and management of health and illness issues, thus acquiring a broader cultural, political, and administrative meaning (Clarke et al., 2010; Crabu, 2018; Thomas, 1972). Specifically, the development of standardised protocols for repeatable and controlled experiments and, more recently, the development of evidence-based medicine, together with a supposedly unbiased understanding framework for biological phenomena, have allowed scientific biomedicine to assert authority over questions of health and illness (Berg & Timmermans, 2003). These developments have enabled the exponents of scientific biomedicine to publicly advocate for the socio-political authority to set their expertise to work in the management of everyday life for the sake of individuals and wider social wellbeing (Conrad, 2005). Indeed, the social relevance of biomedical knowledge has increased not only via the expansion of biomedicine's jurisdiction over human life—both behaviourally and bodily—but also as the basis for a more widespread health-political governance of society (Rose, 2007; Prainsack, 2017). From this perspective, scientific biomedicine provides the cognitive and normative resources by which populations and their governance are segmented on the basis of diverse nosological classes whose overall objectives are both disease control and public health maintenance and improvement. Accordingly, scientific biomedicine circumscribes a politics of life designed to address the vital processes of human existence, thus supplying the shared vocabularies, techniques, and instruments with which scientists, doctors, biotech companies, and individuals address health and illness matters.

Whilst the politics of life play a pivotal role in ordering and configuring the vital processes of human existence (from birth to death and human reproduction and from disease to mental health), over recent decades, scientific biomedicine has become increasingly exposed to social

pressures. This is due to the dominant role played by research scientists and biomedical organisations in framing human behaviours and problems as medical conditions.

Questioning the monopoly of research scientists in defining how health and illness conditions are identified and managed is not in itself new (Mahr, 2021). Indeed, what lies at the centre of this conflict are claims to the right to other forms of knowledge in the approach to the human psychological and biological condition, as the growing consensus on alternative models of caring and healing among both ordinary people and communities of health professions shows (see Brosnan et al., 2018; Gale, 2011, 2014). Nevertheless, this conflict was recently exacerbated, at least in the public sphere (see Crabu, 2023), by the COVID-19 pandemic, during which groups of concerned people claimed that ‘true’ and ‘useful knowledge’ are not necessarily the preserve of science and thus of the prevailing politics of life and its representatives. Indeed, RKC’s developed knowledge—rejected by the scientific community and its practitioners—on how to manage health and wellbeing during everyday pandemic life (Desta & Mulgeta, 2020; Lasco, 2020). In so doing, they also redefined and reinforced key discourses and narratives—often shaping broad arenas (see Chap. 6 by Picardi et al. and Chap. 8 by Morsello et al.)—critically targeting the institutional politics of life as a way of enhancing the legitimacy and public relevance of their refused knowledge claims. As Bijker et al. (2009) argued in a study on the transformation of scientific authority, ours is an era in which the authority of science is being increasingly challenged, at a time when the need for scientific advice is especially urgent (i.e. the COVID-19 pandemic). In this regard, according to the viewpoint of the RKC’s examined in this volume, the institutional politics of life is no longer capable of effectively serving the public interest because it pursues goals conflicting with the welfare of society and stops individuals from making informed health-related decisions.

Two major dimensions of this critique can be analytically identified. The first relates to disputing the conditions and arrangements under which actionable biomedical knowledge is produced. Among RKC’s claim-makers and their followers, a stance critical of biomedical research

methods and technologies leading to disease treatment protocols is common. This first critical dimension is less a matter of questioning biomedical knowledge per se but rather an ensemble of formalised or formalisable epistemic conventions and research practices shared by scientific communities engaged in producing biomedical knowledge. The second target of claim-makers' critiques is a set of political-normative elements that include a health professional approach which has led to an extension of medical power over vital processes, as well as a growing corporatisation and commodification of biomedical research and healthcare practice.

This twofold critique of the current institutional politics of life can be analysed by disentangling two interrelated dimensions of mutual concern:

- Questioning the scientific and technological basis of scientific biomedicine's framing of various aspects of life as medical conditions—that is, the growing extension of biomedical jurisdiction over human beings. Here, RKC's increasingly emphasise individual responsibility and experiential expertise regarding the trustworthiness of a potentially significant corpus of knowledge in personal health management. These RKC's argue that individual health management should involve a symmetrical relationship with health professionals, both allopathic and otherwise.
- Casting doubt on professional biomedical practitioner arrangements. This involves RKC's questioning the institutional status and legitimacy of health professionals and medical experts, who are accused of colluding with, or being subjugated by, global biotech corporations and political elites, and thus working outside public scrutiny.

These two interrelated dimensions echo a phenomenon that has recently been labelled 'science-related populism' (Mede & Schäfer, 2020; see also Bory et al., 2022a, 2022b), to describe the conflict between a (supposedly) truthful and honest general public and an academic and scientific establishment (supposedly) lacking moral principles and engaging in deceitful or fraudulent practices. Accordingly, this conflict arises from the elite's unjustified assertion of authority in

scientific decision-making and the public's rightful demand for greater control over such decisions and the pursuit of truth (Mede & Schäfer, 2020). The science-related populism concept is doubtless relevant to an analysis of the way that public debate on scientific facts and the trustworthiness of scientific institutions can spark complex debates around the social meaning of 'truth'. However, it primarily emphasises the oppositional nature of the conflict between scientific institutions and other competing forms of knowledge.

Indeed, focusing on the two dimensions described above allows us to highlight not only that RKC's are discursively organised around 'counter-factual' arguments regarding biomedical evidence and advice but also that they are mutually committed to elaborating accusations of epistemic weakness and pointing the finger at the socio-political circumstances surrounding the authority of scientific biomedicine and its practitioners. In other words, not only do RKC's challenge the epistemological foundations of biomedicine but they also engage in socio-political critique. They thereby contribute to shaping the knowledge basis for informed decision-making and political engagement in health-related matters. In so doing, they elaborate on a contingent critique of the institutional politics of life as a strategic resource for developing and endorsing refused knowledge itself. Thus, critical scrutiny of the current politics of life constitutes both a predisposition to generate and endorse refused knowledge and part of the attribution of credibility and legitimacy to a body of refused knowledge itself. From this perspective, challenging the prevailing politics of life is therefore complementary to the task of actionable refused knowledge elaboration. Hence, the ways in which RKC's' followers perceive and understand their everyday experiences according to a body of refused knowledge are not independent of the critique of the institutional politics of life's management of health matters and biological human life. A certain degree of ambivalence notwithstanding, this critique is a fundamental basis for refused knowledge claim-makers' arguments regarding the importance of the need for the co-existence of multiple models of caring and healing within public health systems.

7.3 The Institutional Configuration of the Politics of Life Under the RKC Lens

On the basis of the conceptual framework discussed above, the next two sections of this chapter aim to highlight the intertwined critique of both the epistemic and political conditions shaping the biomedical knowledge manufacturing process, as well as the resulting implications for the ways health professionals mobilise this knowledge in public health management. This twofold critique is not merely oppositional but also generative, as it is closely related to a wider shared discursive arena that is relational and supports meaning-making in conferring credibility and solidity on knowledge refused by the scientific and biomedical institutions.

7.3.1 RKC Challenging the Alignment of the Normal and the Pathological

The first issue of mutual concern at stake in challenges to the politics of life regards the scientific and technological arrangements followed by scientists in aligning the ‘normal’ and the ‘pathological’. Or, in other words, refused knowledge claim-makers question the existing configuration of instruments, expertise, biomedical standards, health technologies, and protocols by which research scientists identify and make sense of both normal and pathological biological conditions of the human organism. What is at stake here is a critical examination of the nosographic research that turns certain biological conditions into objects of biomedical concern and intervention. In this regard, RKC criticise research procedures and treatment validation methods within the biomedical landscape, such as evaluations of clinical options via experimental studies, blind assessment, clinical trials, and statistical inferences. In so doing, RKC frame the prevailing therapeutic protocols as a sort of unfathomable ‘black box’ about which people are only allowed to know the inputs (i.e. top-down nosographic classifications of biological conditions) and outputs (i.e. medical treatment) and no more. Hence, RKC view ready-made biomedicine as an epistemic domain based on opaque research procedures. Refused knowledge claim-makers state that people

are no longer bound to accept this biomedical knowledge ‘dictatorship’ and encourage individuals to make their own personal judgements of both scientific evidence and refused claims on the basis of an experiential research approach. Here the case of the 5BL-based social worlds is particularly illuminating:

The statement ‘Expert opinion should be taken as fact: experts know what they are talking about and what do you know about it?’ is false and misleading. However, it is especially important in regard to health that, having listened to experts, we all gather enough information to form our own opinion. I’m talking about opinions because today, unfortunately, the majority of the medical world is completely lacking in irrefutable evidence. Hence, when there is no clear evidence of effectiveness, we must all learn how to gather the correct information and be free to make our own choices. (Quotation from the ‘5BL—The magazine about the 5 Biological Laws’)¹

Well, what has medicine achieved until now? Exactly the opposite of that of the five biological laws. That is, it has established protocols and doctors are no longer free to be doctors. They just have to study the protocols by heart and, in the face of symptoms described by patients use those ten pills or that type of intervention. If a doctor follows the protocols, even if the patient dies he or she cannot be prosecuted, the doctor I mean, because s/he followed the protocols. If the doctor prescribed nine pills rather than ten, then someone can say: ‘No, then you didn’t follow the protocols’. The problem is that we need to understand that there are no protocols, since there are individuals with their perceptions and experiences, and here I need to understand their childhood, understand how they have lived.

(Interview with BL1, claim-makers in the 5 Biological Laws Community)

RKCs view the methodologies and expertise via which biomedicine is believed to represent the truth on health and illness issues with suspicion and distrust, arguing that scientific biomedicine exercises control over public health through untrustworthy protocols with no basis in publicly

¹ The *5BL—The magazine about the 5 Biological Laws* is one of the major online magazines disseminating German New Medicine and the so-called 5 Biological Laws and their application. It is managed by one of the most influential claim-makers within the Italian 5 Biological Laws milieu. Full article available here: <https://magazine.5BL.eu/2017/07/opinione-espertominencebasedmedicine-5227.html>

accountable and verifiable research procedures. Hence, for the RKC, such protocols are harming healthcare practice. In the jargon of some refused knowledge claim-makers, medical experts and scientists are labelled derogatorily as ‘His Eminence’, to denote that trust in biomedicine is currently a dogmatic act of faith, and not an informed judgement based on the reliability and accountability of the research procedures adopted by the scientific community. Further, physicians—in their capacity as users of ready-made clinical protocols—are framed ambivalently, as both perpetrators in a domain based on untrustworthy expertise and victims of this same domain.

On the basis of this critical stance, refused knowledge claim-makers urge their followers to mobilise their experiential expertise to systematically verify the reliability of knowledge—instead of passively accepting institutional scientific enquiry as the sole certified source of truth and knowledge. Whilst sometimes mimicking certain of the argument repertoires and explanatory rhetoric pertaining to the scientific establishment (e.g. citing papers available on online scientific search engines such as *PubMed* which support their arguments and hypotheses), they urge people to treat institutional experts’ advice sceptically and engage in generating and assessing knowledge through experiential expertise (Crabu et al., 2023; Pfister & Horvath, 2014). Thus, RKCs blur the prevailing expert boundaries, questioning the scientific monopoly and viewing experiential expertise as a basis for health decision-making. From the RKC perspective, experiential expertise is a matter of the need to gather a concrete and narratable body of evidence about bodily and psychological experiences not represented in the prevailing scientific domains, and of use both in improving wellbeing, and resisting potentially harmful biomedical knowledge and advice:

I have worked a lot in thoracic surgery and, therefore, I have seen many lung cancers. A surgeon might say, ‘Ah, but this guy smoked ten cigarettes a day!’ Well, I understand that he smoked ten cigarettes a day, but you have to explain to me why the tumour developed only in the upper lobe of his left lung. Why are you not considering this point? Why did the tumour only affect that part? Why hasn’t the tumour spread to all of the lungs? It affected the left main bronchus, and then it affected the upper lobar bron-

chus, and then it stopped there. Why didn't it take everything? And there, and there. ... And they don't know how to answer you. Got it? They can't answer you. They don't have an answer, since they can't see the subtleties of things. This is called reductionism, isn't it? Reductionism. There's one big problem with reductionism: that it leads you to 'It's the smoking'. The smoking? But smoke can affect both lungs. Why did it affect just one part? And why did it cause a bronchial carcinoma instead of an adenocarcinoma, for example. There are some important histological differences that the 5 biological laws can illustrate well. And they don't know how to answer you there. And, therefore, when they don't know how to answer, they also say that it is genetics. And that's how they dismiss you.

(Interview with BL2, claim-makers in the 5 Biological Law Community)

The 5BL RKC's thus maintain that diseases and the clinical and pathological explanations of them by scientific biomedicine are fundamentally based on research procedures that are incapable of grasping the complexities of the human body. What they see as institutional biomedicine's reductionist mind-set has, they believe, led to certain significant factors being underestimated or ruled out, such as the psychosomatic dimension. They argue that restoring centrality to factors such as these, excluded by institutional biomedicine from its domain of expertise, is crucial to developing effective experiential knowledge for individual and public health management. For Alkaline Water RKC's, for example, COVID-19's respiratory symptoms relate to a weakening of our immune systems caused by excessive body tissue acidity that could be effectively treated via an alkaline diet. Hence they argue for the importance of alkalisiation practices as a way of strengthening the immune system:

It seems plausible to assume that the gut is the cause or that it aggravates SARS-CoV-2 infection. The respiratory tract hosts its microbiota, but patients with respiratory infections generally present with intestinal dysfunction, which is related to a more severe clinical course of the disease, thus indicating a relationship between the gut and the lungs. This phenomenon can also be observed in patients with COVID-19. [...] Treating the intestinal microbiota can be a new therapeutic option, or at least an adjuvant therapeutic choice.

(Post on Facebook page by SM, physician, and promoter of alkaline water)

In contesting biomedicine's scientific and technological arrangements, RKC members endorse (naïve) holistic principles to question what they see as the Cartesian 'mind-body' dichotomy on which modern medicine is rooted. They thus attempt to shape new kinds of facts (e.g. psychological shock as a cause of tumour) that institutional health professionals have not yet considered or that they do not even consider to be 'trustworthy facts'. Hence RKC members mobilise their experiential expertise to introduce new kinds of evidence which they see as strengthening the legitimacy of their claims for standing within the refused knowledge domain. For example, where the pro-vaccine choice milieu is concerned, the RKC members seek to 'develop' self-tested protocols to boost the immune system via natural products or food supplements, through peer-to-peer experimentation and discussion:

My 8-year-old son is a non-severe asthmatic. I was thinking of starting to give him vitamin C, whose potential I have only recently discovered, in the hope of getting rid of the bronchial dilator and cortisone. I was wondering what other vitamin or supplement I could combine with vitamin C to improve his immune system? I'm also asking you, in addition to the pediatrician's advice and the info I've already found on the internet, because I think your direct experiences could be just as enlightening. Thank you.

Comment by member B to the original post: I have a disease of the immune system. In addition to vitamin C, I take capsules with powdered Cordyceps mushrooms. It is wonderful in general but especially with tonsil problems.

Comment by member C to the original post: Personal experience ... the first thing to do is to eliminate milk and dairy products, and you will already see big improvements. If I had known before, I would have avoided many drugs, cortisone, and bronchodilators.

Comment by member D to the original post: I started this winter with vitamin C for my baby and for us, and this was the first year without cortisone, antibiotics, and dilators. I hope it will be the same for you.

(Quotations from 'Comilva' Facebook page, 31 January 2020)

RKC members consider experiential expertise on their own bodies significant as well as producing or assessing actionable knowledge making them active players in their own physicality and psyches. They thus juxtapose the scientific and technological background of the current

institutional politics of life with what they consider to be its paternalistic, untrustworthy, and authoritarian form of expertise. From the RKC's perspective, for any specific evidence and information to be accepted as legitimate and true, it must always be tested and experienced directly by those affected. They therefore demand a form of testimonial knowledge based on experiential expertise which they thus deem more credible (van Zoonen, 2012). In this respect, the people involved in RKC are not only proactive in learning more about themselves and their own bodies but they also argue that what they learn must be shared with others for further testing (independently of institutional biomedical expertise) with a view to strengthening a body of knowledge that is both individually actionable and collectively accessible for the management of health outbreaks. In some cases, this knowledge might not yet have been refused by institutional science, since a concerned RKC might still be engaged in validating its trustworthiness through experiential research. In this way, RKC intend to produce fresh evidence, not only for experience-based knowledge acquisition and sharing but also in order to test it on the very practical level of their own needs.

From this perspective, RKC elicit a style of research that is closely bound up with everyday practice. Indeed, most perceive statistical calculations, abstract scientific theories, and technologically mediated representations of biological processes as potential tools of deception. They regard individual stories, series of cases, and variations on situated health- and illness-based accounts as more suitable ways of assessing the knowledge they share about healing and caring. This, RKC argue, is a way to evaluate knowledge which takes full consideration of experiential practices and ideas, and to obtain far more reliable and accountable evidence than that emerging from scientific biomedical procedures, such as randomised clinical trials. In this respect, it should be noted that stances of this kind are widespread among RK claim-makers, although RKC followers more generally take a more nuanced approach, attempting to hybridise institutional biomedical care practices in the light of their experiential knowledge (see Chap. 3 by Paolo Volonté). However weak refused knowledge might appear from the outside, it is both self-experienced and empirical and therefore perceived as valid from within the RKC concerned. Their epistemic stances rely on the intimacy of bodily and

psychological perceptions. What is at stake here is not an ‘impersonal’ datafication approach to the living body but an experiential approach to one’s own body, subjective sensations rather than formalised experimental protocols, more readily understandable individual experiences rather than the expert exclusivity of biomedical knowledge.

In contrasting the epistemic positioning of prevailing biomedicine, RKC’s support a conception of ‘direct empiricism’ by which dependable facts, events, and evidence are those which we are able to perceive directly with our own senses and cognition, needing no mediation and thus no institutional experts and health professionals. Hence, experiential expertise can come across to RKC followers as a better epistemic strategy, based on the concept of the greater reliability of knowledge self-produced by users, a kind of ‘prosumer medicine’ based on direct empiricism.

7.3.2 Contesting the Professional Arrangements of Scientific Biomedicine

The second significant dimension of RKC’s opposition to the biomedical politics of life concerns its questioning of the professional biomedicine milieu. In this regard, health professionals and medical experts are framed as a body of practitioners operating primarily under the control—the yoke—of political elites, global biotech corporations, and ‘Big Pharma’, such as AstraZeneca, believed to have exploited the COVID-19 pandemic to pursue its own political and economic ends. Health professionals, and general practitioners in particular, are depicted by RKC’s as victims of powerful actors (e.g. national medical associations, Big Pharma, medical regulatory agencies) pursuing harmful interests and dominating the institutional biomedical landscape. Subjugation of this sort is seen as potentially preventing physicians from pursuing collective and public health interests. National and supranational political decision-makers operating in the field of public health (e.g. national and supranational medical agencies such as the national health institutes and health ministers) and vast segments of healthcare sector employees are seen as accomplices of the pharmaceutical industries in their pursuit of interests running counter to the public interest, since they might hide effective treatments

or create ad hoc diseases and pandemics in order to sell drugs or subjugate the population:

Once we went to the emergency room. But I don't remember why, my son wasn't well ... and they give us antibiotics. ... I looked at the doctor and I told him, 'Why antibiotics?' I mean, I don't remember the pathology or what my son had that time there. The doctor told me, 'Well, if in doubt, let's give it to him'. I didn't give it to him, and he recovered quietly. It's not so much traditional medicine that I don't trust, but I don't trust those offering it to you, because there are economic interests behind it that are crazy. You want to give antibiotics to my son?

(Interview with FV1, Pro-vaccine choice follower)

[...] A whole industry is developing around cancer, a whole industry, a whole pharmacological, surgical, radiological induced industry. You have no idea about all this. Unfortunately, I do! [...] I work with drugs. Four-five millilitres of drug—I'll tell you, huh?—that's sixteen thousand euros. You can understand that there when anyone, anyone who says, 'I have found the cure for cancer and drugs are not useful!' either they shoot him immediately, directly at the moment he says it, or he is isolated, pilloried by the media or met with deadly silence.

(Interview with BL2, claim-makers in the 5 Biological Laws Community)

For RKC's the institutional biomedical field—and especially the behaviour of those engaged in the practical mobilisation of biomedical knowledge—is inherently biased by the profit logic pursued by biotech conglomerates. Hence, in their view medical health workers' professional practice is thus partisan, since scientific accuracy, the release of open data to public scrutiny and verification, and the evidence-based approach to medicine are ancillary and subordinated to the financial interests of biotech and pharmaceutical corporations. RKC's demand an 'evidential culture' (see Collins, 1998) that considers a variety of experiential findings as potentially relevant data. Indeed, in their reasoning, the existing political and institutional underpinnings of scientific biomedicine allow biotech and pharmaceutical corporations to manipulate the production of reliable evidence on health matters. They believe that the shortcomings of health professionals and scientists can only be offset by other kinds of facts, especially those elaborated by RKC's as non-profit actors. This,

RKCs' claim-makers argue, may compensate for the problem of health professionals and biomedical organisations systematically rejecting, or not producing, knowledge fostering individual and public health.

In this respect, two major issues channel RKCs' critiques of the professional biomedical practitioner milieu. The first concerns the fact that scientists and medical experts are keeping something from people (e.g. the manmade origins of the coronavirus in China or the dangers of electromagnetic pollution to health and the environment). The second is that the practice of biomedical research has alienated itself from its own epistemic roots to pursue profits and develop new forms of individual control and subjection (e.g. mandatory vaccine policies or human genetic therapies):

Do you remember the media panic artificially created to inflate public spending on drugs? Do you remember the conflicts of interest within the World Health Organization? The collusion between national governments and pharmaceutical companies, do you remember them? Do you remember the drugs sold for billions of dollars to all the governments of the world, which only after a few years turned out to be completely ineffective and toxic? In this period of panic for the 'new coronavirus 2020', it is worth refreshing your memory to keep the attention on these potential dangers [...].

(Quotation from the *5BL—The magazine about the 5 Biological Laws*)²

As far as vaccines are concerned, there is a game worth several billion at play, because pharmaceutical companies don't give away vaccines. If we look at Europe, Pfizer, with the production of vaccines scheduled for this year [e.d. 2021], will earn over 30 billion euros. It's a lot of money. The problem is trust: why, then, should I trust someone like Pfizer, which has been found guilty more than once? More than one conviction for violations of human rights, including illegal experimentation in developing countries. It experimented with drugs. ... It experimented with drugs on children, exploiting parents' ignorance, among other things.

(Interview with FV2, Pro-Vaccine choice follower)

² See footnote 1 for details about *The 5BL—The magazine about the 5 Biological Laws*. Full article available here: <https://magazine.5BL.eu/2020/02/coronavirus-2020-panemie-artificiali-mediche-5320.html#ixzz7Wqm4njCt>.

Such concerns have been debated widely within various RKC, thus shaping a broad discursive ‘substantive arena’ (Clarke & Star, 2008) that consolidates a collective anti-establishment stance as a way of raising awareness of the need to combat what is seen as a powerful biomedical elite. Accordingly, as we saw in the previous section, RKC urge their followers to take health research back into their own hands or to check the trustworthiness of a body of evidence via experiential expertise. Experience-based research can be supplemented by alliance building with scientists and researchers seen as independent, such as the Ramazzini Institute³ in Italy. This is an approach taken by the Stop-5G community (see Chap. 5 by Simone Tosoni), which is considered emblematic of ‘good research’ due to its independence of Big Pharma and the biomedical elites. Hence, it is not a matter of rejecting science or an abstract scientific ethos per se. On the contrary, RKC question the moral principles of health professionals, and the professional politics of life approach, which they accuse of having been corrupted by biotech conglomerates in cahoots with the World Health Organisation, the European Medicines Agency, and the medical authorities in general.

The emergence of a cross-RK arena was evident during the COVID-19 pandemic (see Chap. 8 by Morsello et al.). In such circumstances, RKC’s followers considered the pandemic a political tool in the hands of the prevailing biomedical elites designed to control human behaviour and govern public health on the basis of unfounded claims about a supposed global infection outbreak. ‘I am my own doctor’ was, in fact, one of the main discursive *trait d’union* in various RKC during the COVID-19 pandemic. The belief that the dominant biomedical establishment, in league with political elites and biotech corporations, is responsible for a worsening of public health is especially appealing to RKC’s followers. Historically, this stance has also raised a number of extremely radical political demands, especially by the 5BL community (see Bory et al., 2022b), such as the abolition of the Italian Medical Association and the pluralisation of health and healing models, that is institutional

³The Ramazzini Institute was founded in 1987 as a non-profit social cooperative and engages in developing strategies with which to monitor tumours and other environmental non-communicable diseases.

recognition of refused knowledge (D'Amato, 2020). These demands are supported by the conception that the public health authorities have gradually replaced 'evidence-based medicine' with 'eminence-based medicine'. According to the RK claim-makers, this biomedicine governance transition is the result of a growing devolution of public health responsibilities by formal state apparatuses—potentially transparently auditable by concerned groups of citizens—to (quasi)autonomous regulatory bodies (e.g. bioethics committees, medical associations, and institutional expert task forces) and private corporations over whom the only controls are economic benchmarks and budgetary tools. The critiques advanced by RKC to the professional structure of the current biomedical landscape can be framed as a specific political stance aimed at dismantling the hierarchical relationship between scientists, medical health workers, and citizens.

Although academic circles and public decision-makers—especially those influenced by post-truth theories (see Ball, 2017; D'Ancona, 2017; Davis, 2017)—have described RKC as actors whose ideological glue is the rejection of reason, rationality, scientific expertise, objectivity, and democratic values, this reading can be seen as of limited usefulness in understanding the conditions and modalities by which credibility is conferred on refused knowledge. Rather than a prejudiced rejection of science, RKC have raised relevant questions as regards the demand for public participation and the extension of deliberative mechanisms within domains traditionally subject to the jurisdiction of institutional experts, their clearly anti-establishment stance notwithstanding. In this respect, recurrent calls for people to perform their own experience-based research are primarily a matter of demarcating the boundary between 'communities seeking the truth' and a 'corporatised biomedical establishment' and involve RKC and their followers demanding a people- rather than profit-centred approach to public health.⁴

From the starting point of accusations of paternalistic exclusion of ordinary people from an active role in the healthcare system, RKC

⁴ Although claim-makers criticise those they see as profiting financially from speculating on public health, it is worth noting that they themselves sometimes operate as economic agents in search of revenues in their dissemination of refused knowledge (e.g. private consultancy work, book sales, fees for attending teaching events).

outline a range of solutions designed to orient the work of professional healthcare workers and scientists. They argue that the scientific for-profit research style based on the private sector and corporations should be replaced by a more public search for knowledge engaging a range of subjects and experiential expertise. RKC's seek to challenge what they see as the political and economic underpinnings of biomedicine and its exclusion of people from the management of their own wellbeing, which remains the exclusive preserve of corporate biomedical elites. The demystification of the political and economic interests surrounding the professional stance embedded in the biomedical politics of life is thus critical to publicly legitimising refused knowledge:

Not believing the dogmas of official medicine is simply not seen as possible. The absolute usefulness of official medicine is paralleled with the usefulness of essential infrastructures, such as water supplies, sewers, roads, schools. We are more or less free to treat ourselves with alternative methods, but we are not free to refuse to pay for the official medical system, or to refuse to submit to its rules.

(Quotation from a blog by BL3, June 12, 2021)⁵

From this perspective, RKC's attempt to challenge the institutional political decision-making domain on the grounds that health professionals' formal rules are detrimental to public health. They question such rules rather than merely identifying the responsibilities and biases of individual health professionals and research scientists. They also claim that—even when it appears neutral and objective—the public health political decision-making embedded in the politics of life actually conceals rationalities that do not serve people's, or society's, wellbeing. This point is significant as regards the process by which refused knowledge is accorded credibility and legitimacy, since RKC's believe to be engaged in a struggle aimed at ensuring that the healthcare system's shortcomings are tackled for the sake of society.

Overall, a twofold strategy emerges from an analysis of the second critical dimension of the institutional politics of life. The first of these is oppositional and concerns identifying an 'enemy', that is an object or

⁵The full article can be accessed here: <https://usciredallorrore.wordpress.com/2021/10/19/dittatura-medica-riconoscerla-per-combatterla/>

(collective) subject to blame for what has been institutionally constructed and/or is perceived as a problem for individual and public health. For instance, the ‘World Health Organization–Big Pharma–national health institute’ alliance is blamed for the founding of a politics of life regime that does not serve people’s fundamental rights and wellbeing. A second strategy concerns identifying people themselves and interaction between peers as alternative sources of truth as regards research into living bodies and the production of dependable wellbeing management knowledge. These two strategies outline an alternative approach to healthcare and knowledge practice, since they encourage people who feel that their health issues and concerns are being neglected by the biomedical establishment to mobilise their own experiential expertise in the search for new evidence collectively. In so doing, RKC’s are attempting to demarcate a boundary between their own search for the truth, and that of political elites, biotech corporations, and subjugated health professionals.

7.4 Uncovering (Allegedly) Hidden Truths in Challenges to the Politics of Life

This chapter has highlighted that the processes involved in according legitimacy and credibility to a body of refused knowledge are closely bound up with critical discursive production targeting the politics of life. This critique orients the collective commitment to action in the construction of refused knowledge whilst also working to enhance the credibility and legitimacy of such knowledge. In fact, in the critical scrutiny of the epistemic, professional, and political knowledge production and mobilisation status quo, RKC’s question the ways governmental bodies, biomedical agencies, and the scientific community control, manage, and reshape human beings’ biological components and value as living bodies. The shaping and legitimising of a corpus of refused knowledge is intertwined with a twofold critique of the institutional politics of life relating, on one hand, to the scientific and technological arrangements and, on the other, to the political and professional framework underlying its practical exercise. Generally speaking, RKC’s view the institutional politics of

life as an ensemble of epistemic conventions, regulatory tools, and professional and political arrangements designed to exclude individual agency from healthcare decision-making. Dominated by a colluding coalition of biotech corporations, political elites, and medical authorities, the politics of life, RKC's argue, reproduces power asymmetries between health experts and citizens, for the primary aim of pursuing its own profits, and is thus inherently incompatible with the collective good. From this perspective, not only do RKC's argue for the need to accord individuals a greater say in the management of their own wellbeing—thereby questioning the biomedical practitioner monopoly over health matters—but they also question the scientific, technical, professional, and political conditions by which biomedical knowledge is produced and rendered actionable in everyday life. Accordingly, they argue that other kinds of facts, evidence, and expertise, such as experience-based facts, must be recognised. Although RKC's are publicly stigmatised for disseminating hoaxes and fake news (Farkas & Schou, 2018), the production of refused knowledge can also be alternatively (and less normatively) interpreted as a search for experiential truth. Theirs is, in fact, direct empiricism based on individual experience rather than formal laboratory-based protocols. By mobilising their experiential expertise, sometimes in alliance with independent scientists, RKC's consider themselves to be engaged in uncovering hidden truths concealed by the biomedical establishment and political elites and their followers thus undertake experience-based research on their own bodies and minds with a view to producing and testing the trustworthiness of facts and evidence neglected or rejected by institutional biomedicine.

If we consider the importance accorded to experiential expertise, it is clear that RKC's followers testing a body of knowledge for themselves is an epistemic strategy by which they see themselves as speaking the truth about health and illness issues. For example, RKC's engaged in a collaborative elaboration of the COVID-19 pandemic through self-disclosure practices—mainly on digital platforms (see Crabu et al., 2023)—involve sharing personal health information with others and making sense of the policy decisions of biomedical agencies and political decision-makers (e.g. lockdowns and compulsory vaccination) seen as distant from their everyday empirical experiences.

Here, it is worth highlighting that refused knowledge claim-makers' suspicion of laboratory-based research, computer-based simulations, and clinical trials as determinant procedures in the alignment of the normal and the pathological is bound up with holistic assumptions, together with a principle that individuals cannot be reduced to general nosological classes. One of RKC's criticisms of the institutional politics of life is that biomedical research is founded on the idea that, biological specificities notwithstanding, individuals have sufficient common biological features for the same symptomatology or diseases to be addressed in the same way. By contrast RKC's argue that, similarities between individuals notwithstanding, people displaying the same symptomatology may need treatments to be specifically tuned to their own idiosyncratic experiences, both bodily and psychologically. Thus, RKC's do not regard experiential expertise merely as an epistemic approach to knowledge but also as a strategic relational resource with which to legitimise their refused knowledge in the public domain by placing individual specificities centre stage in their healing models. Indeed, RKC's commonly focus on individual descriptions of cases of 'successful' healing rather than 'abstract' statistics and models, when trying to persuade others of the effectiveness of their refused knowledge.

In sum, in questioning the politics of life, RKC's are attempting to break down institutional expertise boundaries with other kinds of expertise, not simply affirming new sorts of facts, evidence, and healing models but also attempting to question the health regulatory decision-making process. Hence RKC's' approach to knowledge, whilst refused by the scientific community, demonstrates a perspective to individual and public health which is on the margins of a biomedical establishment accused of acting more or less covertly for its own gain and mostly to the detriment of the public good. Here, it is important to highlight a point that may be worthy of attention from future researchers: although RKC's are actively engaged in disputing the current institutional politics of life status quo, their main health and wellbeing focus is actually the individual rather than the collective level. Indeed, it should be noted that whereas RKC's share a general propensity for social change, especially concerning the authoritative position of scientists and healthcare professionals in society, they do not share a ready-made, authoritative set of political arguments

or a general theory of social transformation. Therefore, what they tend to outline and hope for is a sort of individual struggle to free ourselves of what they see as the illegitimate power exerted by the state in cahoots with industrial conglomerates, rather than a collective transformation of power relations between citizens and what they call the biomedical elites.

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8

“This is the real face of Covid-19!”: How Refused Knowledge Communities Entered the Pandemic Arena

Barbara Morsello, Federico Neresini,
and Maria Carmela Agodi

8.1 Introduction¹

The Covid-19 pandemic was an unprecedented global health crisis which promoted a generalised process of knowledge production and storytelling, by both institutional experts and lay people, devoted to finding a way of preventing the virus spreading and understanding what was

¹ The chapter has been conceived and discussed by all the three authors. In compliance with Italian academic folkways, Barbara Morsello, Federico Neresini and Maria Carmela Agodi acknowledge that the former wrote paragraphs 8.3 and 8.4, Federico Neresini wrote the paragraphs 8.2 and 8.5 and Maria Carmela Agodi wrote paragraphs 8.1 and 8.6.

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happening. Especially during the initial phase of great uncertainty, the health policies adopted by governments fostered public contestation, in which context the RKC's gained a prominent place on the public sphere. Using RKC jargon, these forms of public contestation were designed to uncover the 'real face of the Covid-19 pandemic', i.e. the weakness of the interpretations provided by the public institutions and science along with the potential for alternative explanations, and therefore of different policies to cope with the problematic situation created by the virus.

To increase our understanding of RKC engagement in the public controversy around the pandemic we performed digital ethnography (Hine, 2000; Hine, 2004; Marcus, 1995; Marres & Moats, 2015) during the first months of the Covid-19 outbreak in Italy, with the aim of analysing how the health emergency created the conditions for RKC's to act collectively to oppose the mainstream narratives and policy measures adopted by the public institutions and supported by scientific experts, as well as official media. The data gathered was organised into social world maps (Star, 1989; Star, 2010; Clarke, 2003; Clarke & Star, 2008) designed to analyse (1) the key-actors involved in the RKC's' social worlds and the contestation arena; (2) the relationship networks between key-actors and the evolutions in these; and thus (3) how both the composition of the networks and the connections between key-actors changed over time.

Observing the evolution of RKC's over time provided a valuable perspective with which to understand the mobilisation of refused knowledge within sense-making processes and its implications in reshaping the relationships between RKC's in the pandemic arena. In particular, it enabled us to analyse the pivotal role played by the heterogeneous actors who actively contributed both to facilitating alternative understandings of the pandemic between lay people not fully convinced by the prevailing interpretation and to spawning new social worlds in which diverse RKC's progressively coalesced in the pandemic arena.

These key actors can be grouped into three main categories: non-humans (the virus and the array of new objects the pandemic put in the forefront, such as, e.g., face masks and vaccines), the RKC's' experts, and those of their 'enemies'—namely science and public institutions—who they treated as 'impostors'. The objects which acquired new meanings within the pandemic context can be labelled 'pandemic objects', while 'impostors' (Woolgar et al., 2021) is the definition given by RKC's to

scientific experts, especially those considered part of the ‘academic elite’ which supported and validated the mainstream interpretation of Covid-19 as a global health risk for the entire population. From the RKC’s perspective these experts—scientists or scientific institutions—were to be considered *impostors* because they legitimised lockdowns and other anti-Covid measures interpreted as beneficial to pharmaceutical companies and/or a state strategy to increase its control over citizens.

In summary, this chapter examines how refused knowledge —i.e. the counter narratives employed by RKC’s to dismantle the prevailing Covid-19 pandemic narrative— fostered favourable conditions for the emergence of new alliances between RKC’s, leading to their collective engagement in contesting institutionalised health policies.

8.2 Dealing With Competing Narratives and Actors in the Public Covid-19 Pandemic Arena

Competing narratives regarding the outbreak of Covid-19 succeeded one another in the early stages of the emergency. During this period, the stringent policies implemented by the Italian government to contain the virus attracted frequent criticism, both in Italy and, at times, abroad (Viola, 2022).

Various actors including scientific experts, institutions and the mainstream media occupied the public scene but were not always effective in providing clear and convincing explanations of what was going on. At these uncertain early stages, but also throughout the whole Covid-19 pandemic, a key refrain repeated constantly by most institutional leaders was ‘follow the science’ (Pérez-González, 2020; Stevens, 2020), a claim which made science synonymous with truth, objectivity and evidence-based rationality. ‘Follow the science’ was thus the Covid-19 mantra (Safford et al., 2021), extensively used by institutional spokespersons and politicians (Crabu et al., 2021). However, an increasing number of people began to see all mainstream information circulated by public institutions and their experts as partisan (Desta & Mulgeta, 2020; Prasad, 2021). These people generally embraced a wide spectrum of refused

knowledge involving both ‘doing their own research’ (Attwell et al., 2018) on the web and forming relationships in their everyday lives with others who ‘think like them’. This process led to a juxtaposition of pandemic discourses in which the science-based evidence and institutional experts were opposed to the so-called conspiracy theories and fake news (Bisiada, 2021). Social media played a pivotal role in polarising public discourse (Zollo et al., 2015) in ‘quarantined society’ (Aiello et al., 2021) by amplifying the divide between what was considered *refused knowledge* and *science*. Social media also played a fundamental role in organising dissent (Pavan & Felicetti, 2019) around the official interpretation of Covid-19 and counteracting anti-Covid norms by fostering the organisation of the public demonstrations that filled Italy’s main squares in 2020 and 2021. These protests, however, were not only an expression of discontent regarding public policies but also an attempt to promote an alternative vision of the pandemic supported, shaped and circulated by RKC. To increase our understanding of the ways various RKC connected into new social worlds opposing science and institutions within the pandemic arena, we focused on the discursive practices employed in online interaction settings (from Facebook groups and pages to related blogs and YouTube channels—populated by the main Italian RKC; see the Introduction to this volume).

In view of the pandemic’s evolution in Italy, we organised our online ethnography, during the onset of the emergency in Italy into three main phases (Table 8.1).

The first phase (T1) was characterised by profound uncertainty within RKC as the outbreak of the virus disrupted any possible interpretative framework, giving rise to concerns and doubts.

Table 8.1 Observation periods related to the outbreak of Covid-19 in RKC in Italy

Phase	Selected period	Key event	How RKC coped with pandemic
T1	26 January to 9 March 2020	Arrival of COVID-19	Uncertainty and isolation
T2	10 March to 4 April 2020	Total lockdown in Italy	Latent collective action
T3	5 April to 30 June 2020	Lighter lockdown in Italy	New relationships between RKC and collective mobilisation

During total lockdown (T2) the public institutional explanations and health recommendations were seen as increasingly less convincing to the RKC. Concurrently, this set the stage for the building of alternative knowledge and the defining of new action plans. Within these processes, some individuals gained credibility and were progressively recognised by the RKC as authoritative experts. Moreover, a wide range of non-humans, including the virus and other pandemic-related objects such as face masks, drugs, epidemiological data and tests (hereafter *pandemic objects*) were reinterpreted by RKC as enemies or allies. For instance, Covid-19 tests were seen by many RKC as both an instrument of social control serving the interests of the state and the establishment and a necessary travel and work measure or to avoid lockdowns.

Thus, during the third phase (T3) some key-actors played a decisive role in promoting public action. This occurred when the identification of shared experts and adversaries by different RKC created the conditions for public mobilisation. Consequently, the formerly isolated RKC generated new social worlds capable of actively engaging in the public sphere to promote 'their truth'.

A consideration of these three phases was then the basis for an analysis of the way Covid-19 and the related pandemic objects opened up new contestation possibilities, with digital ethnography clearly showing that the RKC dealt with this uncertainty by turning to their own experts as knowledge providers even if this knowledge was strongly refused by the scientific institutions and medical agencies and then scapegoated by the mainstream media. Significantly, pandemic objects were key-actors, especially during the first phase, becoming a matter of mutual concern for RKC and fostering communications and alliances between them. This favoured the advent of the RKC's experts as new epistemic resources with a view to making sense of the pandemic and organising RKC 'resistance' against institutional power supported by scientific experts. It was in the wake of this that scientific exponents became *impostors* for RKC, i.e. common enemies embodying everything the RKC were opposed to. Framing scientific experts as impostors, moreover, was part of the reciprocity process (see Chap. 1) by which RKC legitimised their experts as the only sources of knowledge which could be trusted.

In phase two (T2), RKC experts and institutional spokespersons labelled as *impostors* began to play roles that can be analytically denominated ‘boundary objects’ (Star & Griesemer, 1989) as they were ‘plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites’ (ivi, p. 393). STS have underlined the importance of boundary objects during emergencies and crises (Tim et al., 2013), as a set of socio-material arrangements existing between social worlds and helping to facilitate communication between them (Bowker et al., 2015; Star & Griesemer, 1989). Once the opposition between RKC’s experts and impostors was established, the refused knowledge interpretation of the pandemic was strengthened and common ground between RKC’s by which new social worlds challenged institutional authority was identified (T3). Furthermore, pandemic objects also played a pivotal role in this phase, embodying the narratives employed by the RKC’s experts and facilitating the interactions between different RKC’s, thus catalysing dissent in new social worlds, at both national and local levels.

8.3 Pandemic Objects and Their Counter Narrative

During the Covid-19 pandemic many new—or newly framed—objects made their appearance in our everyday lives: masks, vaccines, antigenic and molecular tests and tracing apps, along with web platforms and social media to disseminate information.

The pandemic object discourses that circulated on social media in particular—a favourable vantage space on which to share experiential knowledge (Bory et al., 2021; Van Zoonen, 2012)—were fundamentally important in fostering the emergence of counter narratives regarding Covid-19. Memes, posts, images and instructions on the use of tests, e.g., were common tools employed by RKC’s with a view to making sense of Covid-19. As de Saint et al. (2022) have shown, during the pandemic meme production and circulation increased exponentially and this was often associated with hyper-polarisation, online activism and the

distribution of huge amounts of contradictory information, some of which was rejected as fake news by institutional actors. By analysing the memes and posts employed by RKC in shaping their Covid-19 pandemic narratives, e.g., it can be observed that face masks were seen right from the outset as symbols of the subjugating power of the institutions and thus occupied an important position within RKC’s sense-making processes (see Figs. 8.1 and 8.2).

For example, from the very outset of the pandemic face masks attracted the attention of the Pro-vaccine choice and Stop 5G RKC as embodiments of social control. Face masks—considered to protect against contagion in the official view—were, for RKC, symbols of the state’s attack on freedom of speech, like a gag over people’s mouths. For RKC followers, face masks thus weakened people rather than protecting them. This interpretation was shared by 5BLs and Alkaline Water RKC followers. This latter, moreover, depicted the use of face masks as a serious threat to public health, since people wearing masks breathe in their own carbon dioxide. Some RKC’s experts pointed out this danger for children in particular, thus creating common ground between Alkaline Water and Pro-vaccine choice RKC always interested in children’s health.

Another pandemic object that played a significant role was the contact-tracing app Immuni introduced by the Italian Government as a voluntary Covid-19 infection case tracking measure. The app used Bluetooth technology to alert users exposed to infected people, even if they were asymptomatic. During the lockdown (phase T2) in particular, whilst the app was presented as a possible way out of social confinement, it was reinterpreted by the RKC’s experts as key to a heated public personal data security debate. The RKC’s experts depicted the app—like the face mask—as a controlling strategy wielded by the government to obtain personal information on citizens. During T3, Immuni was thus a crucial issue in many public demonstrations across various RKC. Hence, after the Immuni app was launched on 1 May 2020, a digital strike² promoted by Stop 5G was supported and widely disseminated by the Pro-vaccine choice movement, too, as this post shows:

²The digital strike consisted of 24 hours of disconnection from all digital platforms.

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SARS, suina e aviaria, ma anche morbillo e tetano, perché no.

Afta epizootica e mucca pazza e cimurro; zika, malaria e peste.

Quelle servivano ad addomesticare la plebe. Ora la plebe va controllata.

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Fig. 8.1 'The business of terror': face masks as symbols of how the financial profits of the Big Pharma is prioritized over people's health, editorial paper published on the Corvelva Association website. (Source: <https://www.corvelva.it/en/speciale-corvelva/papers/pandemia-il-business-del-terrore.html>)



Fig. 8.2 Face masks as symbols of social control. Reworking by the authors of a meme used on a Pro-vaccine choice RKC's Facebook page on 31 January 2020

The government will impact on the freedoms and lives of every Italian through 5G, artificial intelligence, digitalisation and robots, undermining even inviolable constitutional rights. The Immuni app, digital schools, smart working, permanent and ubiquitous hyperconnection, the installation of at least one million new telephone antennas and the irradiation of all Italians with risky radio frequencies, non-ionising waves and possible carcinogens will have the same effect. ... The best answer? Join the DISCONNECTION DAY, the European digital strike day promoted by the European and Italian Stop 5G Alliance. (23/04/2020 Transcription of a Stop 5G Community re-post on a Pro-vaccine choice Facebook page.)

The post reported above shows that the Immuni app was framed by RKC's as a tool serving the social control role embodied by other pandemic objects including face masks and soon became a shared Stop 5G and Pro-vaccine choice concern. Immuni effectively has been interpreted both as restrictions on people's freedoms and as a health danger: the Stop 5G RKC, in fact, considered Immuni dangerous because it implied

constant use of mobile phones and hence exposure to electromagnetic waves.

The alleged harmfulness of the app thus elicited new alliances between RKC's against the Italian government with supporters refusing to download the app and organising meetings with their experts about the risks associated with using it. Furthermore, the four RKC's also worked together to find ways of staying healthy in a more "natural" way and not getting vaccinated when the vaccine—i.e. the solution most favoured by public institutions as a way out of the pandemic—became available. In this context, Hyperimmune Plasma Therapy (HPT) soon became a sort of RKC Holy Grail. HPT was an experimental therapy introduced during the first stages of the pandemic in Italy based on people with Covid-19 being inoculated with blood samples containing antibodies from people who had recovered from it to counteract the virus. From the RKC's point of view, this therapy embodied the positive value of "natural healing", as a "people to people cure" contrasting with official medicine and of course the vaccine, both perceived as artificial entities produced mainly for financial profit by pharmaceutical companies. For RKC's, in fact, the distinction between "natural" and "artificial" is what demarcates the boundary between the knowledge they trust and institutional science (Gieryn, 1983; Greenhalgh & Wessely, 2004; Gross et al., 2015). Its "naturalness" makes HPT a more reliable treatment in the RKC's view, because it reflects the principles of "pure" medicine working for the good of the people, rather than the economic interests of Big Pharma. News, posts and videos regarding the beneficial effects of HPT and its "low cost" for people affected by Covid-19 spread like wildfire among RKC online groups.

Hence, in March 2020 HPT became a new pandemic object and a controversial issue in the public sphere at the centre of an epistemic battle between those who supported its validity—such as certain physicians and Pro-vaccine choice adherents—and those who later denied its efficacy, such as the Health Ministry and medical public institutions. However, this was not a linear process: initially, people recovering from Covid-19 were invited for blood donations even by health institutions for care or

clinical trial purposes.³ Later, several studies confuted the effectiveness of the therapy⁴ but leading RKC experts still explained how the therapy works and why it was to be considered a valid treatment against the virus instead of artificially created vaccines, as this online post shows:

Friends, today too we have good news: the treatment exists and costs next to nothing. It is called hyperimmune plasma. Prof. Giuseppe De Donno—Head of Pneumology at Carlo Poma Hospital in Mantua—commented on the radio: “At the moment, plasma is the only specific drug against Covid”. But instead of congratulating and sharing the excellent news, Burioni, the official voice of the mainstream networks, replied that plasma has limits. Along the lines of, ‘let’s dampen enthusiasm and, above all, snuff out the hopes of the millions of Italians who have been locked in their homes for two months! Better keep telling them to walk around like zombies in dirty masks and gloves.’ [Burioni and his colleagues] are not experts or scientists who insist on their politics of terror. (4/05/2020 Transcription and translation of a Pro-vaccine choice Facebook post)

Meanwhile, RKC continued to support HPT as a “symbol of democracy”, firstly by Pro-vaccine choice supporters, and then by other RKC as a low-cost solution to the Covid-19 pandemic. Hence, HPT, like face masks and the Immuni app, fostered new connections between RKC, especially after the suicide of De Donno, the physician who supported the therapy’s validity, a highly important development because the doctor-as-martyr-ignored-by-official-science concept is a recurring theme in RKC narratives (see Chap. 4).

During our digital ethnography memes were also of use in increasing our understanding of the impact of pandemic objects for RKC and in shaping their Covid-19 concerns (see Fig. 8.3).

³ There were many calls for blood donation, e.g. the National Center of Blood Donation in Italy: https://www.avis.it/wp-content/uploads/2020/06/Prot.-n.-1296.CNS_.2020_Donazione-di-plasma-da-convalescente-COVID-19.pdf (28 December 2022) or that of the Ministry of Health: <https://www.donailsangue.salute.gov.it/donaresangue/detttaglioNotizieCns.jsp?lingua=italiano&rea=cnt&menu=newsMedia&sottomenu=news&id=33>.

⁴ The largest study in Italy was the Tsunami study: <https://www.aifa.gov.it/en/-/covid-19-studio-tsunami-il-plasma-non-riduce-il-rischio-di-peggioramento-respiratorio-o-morte>.

A popular meme illustrates the idea that these new objects, now part of “quarantined society” everyday life (Aiello et al., 2021; Bisiada, 2021) had configured a new citizen subject to constant control by apps and wearable devices, made obedient by masks and thus perfectly integrated into surveillance society (Fig. 8.3). Pandemic objects thus prefigured not only a specific idea of the future but also new forms of biocitizenship (Petrakaki et al., 2021; Rose & Novas, 2005) which RKC’s attempted to defend themselves against. However, whilst all the RKC’s analysed pursued a specific idea of alternative care (Crabu et al., 2022) and citizenship

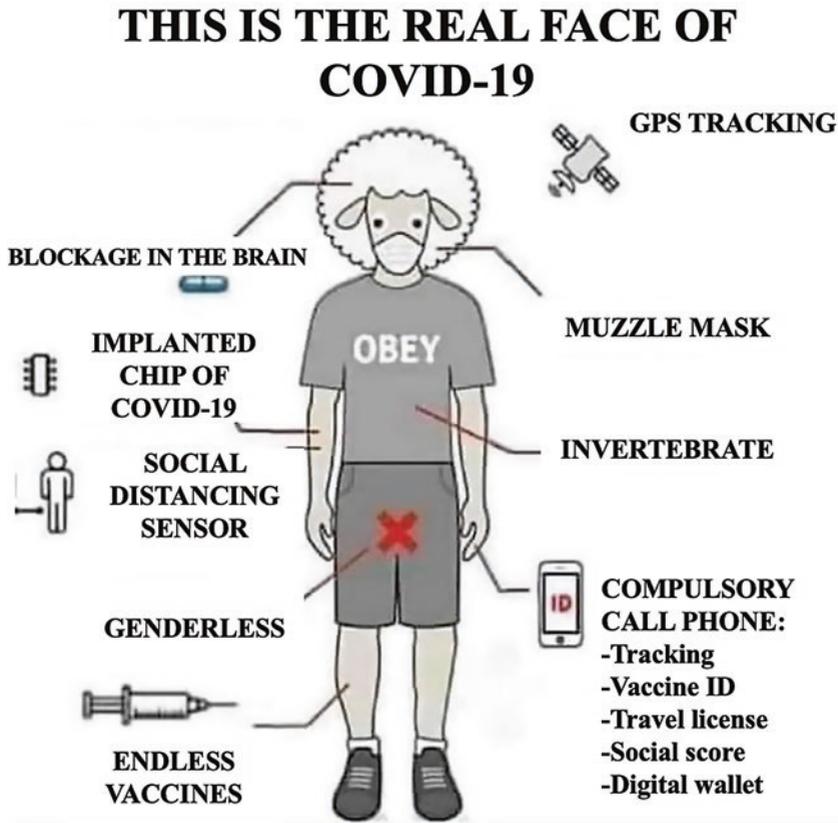


Fig. 8.3 Reworking by the authors of a Pro-vaccine choice RKC’s Facebook meme, 26 May 2020

(Morsello & Giardullo, 2022), prior to the pandemic they had focused on the various objects embodying their visions and claims (vaccines, 5G, alkaline water, biological laws). Pandemic objects, on the contrary, provided an opportunity for RKC’s to build their own truths regarding Covid-19 and beyond, thereby contributing to mobilising experts and identifying common enemies.

8.4 Building Alliances, Organising Dissent: Experts and Impostors as Boundary Objects

During the health crisis scientific experts were the most reliable and trusted actors in Italy and their advice was taken extremely seriously (Capano, 2020), playing a pivotal role even in policy-making terms (Neresini et al. 2023). However, experts were also the subject of controversy over pandemic management based on the available scientific knowledge (Lavazza & Farina, 2020) and this was the context in which they were framed as impostors by RKC’s.

Our online ethnography also showed that the RKC’s identified their own experts, of importance not only in providing actionable knowledge coherent with the interpretative frameworks on which RKC’s rely, but also fundamentally strategic to demarcating the boundaries between reliable knowledge and partisan information, i.e. that provided by impostors. Two main experts—Professors Stefano Montanari and Luc Montagnier, who played the strategic role of boundary objects as they shaped and promoted a specific interpretation of the Covid-19 pandemic among RKC’s—can be identified. The narrative promoted by these experts was flexible enough to adapt to RKC’s that were separate social worlds prior to the pandemic and could be used to support their individual claims. The fact that both Montanari and Montagnier possessed academic credentials (such as PhDs or research grants, even a Nobel Prize in Montagnier’s case) was considered significant by RKC’s in their challenges to the epistemic authority of impostors, capable of simultaneously offering a cohesive version of the pandemic emergency congruent with RKC’s’ approaches to health and well-being.

It is worth noting, in fact, that expert status is not simply a matter of professional qualifications (Stehr & Grundmann, 2011; Nowotny et al., 2001; Gibbons et al., 1994) but also of attribution processes enabled by people and communities. Those recognised as experts provide useful answers to relevant questions (Collins & Evans, 2007; Martin, 1991; Peters, 2008), thus setting priorities for action (Grundman, 2017) as happened during the Covid-19 pandemic when uncertainty around the virus needed to be responded to.

Stefano Montanari, e.g., is a qualified pharmacist who founded the Nanodiagnostics Lab and his thesis regarding the potential risks of vaccination has made him well-known in Italy despite this having been critiqued by official experts and institutions. During the lockdown in Italy (T2) he described Covid-19 as “a flu virus” with low pathogenicity that would not normally cause death. Montanari further explained that it was extremely infectious but harmless, with no symptoms in the majority of people. He assumed that virus mortality was very low, especially for young and healthy people, attributing the high death rates to wrong classification by official health institutions failing to distinguish between those dying of the virus and those dying of other causes whilst testing positive for the virus. Therefore, some videos circulated online by the various RKC argued that the institutional pandemic data was intentionally overestimated to justify the government’s anti-contagion measures, ranging from lockdowns to social distancing, face masks, tests and apps. These measures were described by Montanari as mere tricks to enhance people’s willingness to accept control. Scientific community intervention was required to reject this hypothesis and encourage the public to accept the mainstream explanation of the pandemic. However, it was precisely for this reason that Montanari became a sort of “world human heritage” for RKC (28/04/2020, to paraphrase an AW Facebook post) because his interpretation contributed to empowering RKC members against vaccination policies.

Another expert mobilised by RKC in their attempts to offer interpretations of pandemic objects capable of combating the public version was Luc Montagnier, winner of a Nobel Prize for Medicine, ostracised by the scientific community in recent years for his controversial theses on various issues concerning human health. Montagnier proposed an alternative

to vaccinations and quarantine consisting of boosting immune systems with fermented papaya and glutathione and avoiding contact with infected people. These recommendations attracted RKC’s attention through specific YouTube videos and Facebook posts, on the strength of their tendency to look for online health information.

Moreover, regarding the origin of COVID-19, Montagnier mooted the possibility that it may have originated in a laboratory in Wuhan, China, and not in a wet market, as previously described in official reports⁵ during T1:

Even if it is assumed that the virus came out of a military laboratory, it is also true, data in hand, that its mortality is less than a ridiculous seasonal flu. In the last 4 years, the flu has killed over 68,000 people in Italy, but despite these important figures, no one has ever dreamed of blocking entire cities with soldiers and police or closing hospitals and schools for several days. Why did the unthinkable happen this time for a handful of those dead, almost all very old and/or very sick? Do they want to mentally get us used to a police state, testing to what extent we are willing to give up our freedoms? (29/2/2020, Transcription and translation of a video posted in a Pro-vaccine choice online community)

His hypothesis became an integral part of RKC’s narratives during the lockdown (T2) and throughout the reconfiguration of RKC relationships.

Summarising, then, Montanari and Montagnier argued as follows: (a) Covid-19 works like a flu virus and is thus not dangerous for most people; (b) it originated in a Chinese laboratory and the public action taken to prevent it spreading are excuses for state social control; (c) people can overcome the virus through self-care and by keeping informed. This “truth”, as it was considered by RKC’s, became a useful resource for those challenging the epistemic authority of science (Harambam & Aupers, 2015; Rosenfeld, 2021) and counteracting institutional health policies such as wearing face masks, being vaccinated and social distancing.

⁵Today official sources are “moderately confident” that the virus may indeed have come from a laboratory: <https://www.theguardian.com/world/2023/feb/26/covid-virus-likely-laboratory-leak-us-energy-department> (Last access: 02/03/2023).

It thus might be said that pandemic objects triggered RKC experts' action, enhancing the visibility of RKC's shared interpretations of the pandemic, showing that an alliance was possible. Both Montanari and Montagnier, and their counterpart the impostors, played a leading role in reconfiguring relationships between RKC's because these latter nurtured, shaped and circulated an understanding of the pandemic which RKC's could fight, with a view to disclosing the "real truth" behind the health emergency.

During the transition from the latency phase, during lockdown (T2), to the end of lockdown, when RKC's collectively contested the anti-Covid norms and fought for their truth in the main Italian squares (T3), three main impostors occupied a prominent position, i.e. two health institutions, the World Health Organization (WHO) and Italian Institute of National Health in Italy (INH), and an individual, Professor Roberto Burioni, Italian virologist and immunologist. Burioni, WHO and INH were seen as impostors by RKC's firstly because they were viewed as embodying scientific institutions representing the state and, secondly, as they were a constant presence in the traditional media. In fact RKC's distrust newspapers and television, preferring other information sources such as the web, blogs and self-vindicated independent TV channels such as Byoblu (see below).

Moreover, RKC's maintain that one of the ways impostors influence public opinion is through data manipulation. Thus, in the initial Covid-19 phase (T1), RKC's accused the WHO both of providing false epidemiological data and of describing the virus as a serious threat and a global danger, while in their view it was simply a flu outbreak. Therefore, one of the strategies adopted by RKC's to refute the mainstream interpretation was "revealing" of how data is manipulated by impostors:

The WHO data did not take into account asymptomatic cases of Covid-19 or cases in which symptoms were minimal. In other words, as there were many mild cases of Covid-19 that went undiagnosed because many people did not go to the hospital to be tested, diagnosed and reported, it was hard to come up with a reasonable estimate of how lethal Covid-19 was when compared to other infections. Experts disagreed with the WHO's death rate, claiming that the true rate was much lower. (23/03/2020, Transcription and translation of a post circulated on a Pro-vaccine choice Facebook page)

The RKC’s challenged the epistemic authority of science by formulating alternative accounts of the “real truth” and “what’s behind it”, resisting the “truth regime” through which science is accorded “the legitimate power to define, describe, and explain domains of reality” (Gieryn, 1999, p. 1). There is nothing accidental about the fact that another strategy to fight those considered impostors is undermining their epistemic authority by comparing various sources or by contesting their research methods:

Attention: The WHO statements and the consequent decrees issued by the Council of Ministers (DCPM) are not based on scientifically proven facts! We invite you to carefully read this statement by Fabio Franchi, a physician specialising in hygiene, preventive medicine and infectious diseases. (22/04/20, Transcription and translation of a 5LB Facebook post)

The INH was also consistently challenged in these terms by the RKC’s for its pandemic data. In particular, the RKC’s not only contested how such data was collected but also delegitimised the anti-Covid-19 norms, by reframing the adoption of the face masks as a health risk, as the post below clearly shows:

The INH has just published a paper on the virus’s survival time on various surfaces. It is interesting to note that it survives 4 days inside masks and 7 days in its outer layer. Now they will finally find out that the masks they use and reuse for several days to save money are teeming with bacteria, fungi and other known pathogens. It is no coincidence that there is not a single scientific reference on the WHO website certifying the usefulness of protection from viruses! (24/05/20, Transcription of an AW Facebook post)

Another strategy countering impostors is stigmatising them, as in the case of Burioni. The RKC’s even coined the term “Burionismo” for a specific way of thinking defined as populist, anti-scientific and authoritarian—a sort of “(official) medical populism” (26/03/2020, to paraphrase a 5BLs Facebook post):

Burionismo is the greatest harm of the last Italian decade. Years of brain-washing have led us to where we are now. But the scientific community is anything but Burioni-esque. Slowly, in the coming weeks, the real

scientists will poke their heads over the parapet, and I hope there will be a showdown. (12/03/2020, Transcription and translation of a 5LBs Facebook post)

Since then, the name “Burioni” has become a label stigmatising the RKC’s enemies: people perceived as arrogant and socially dangerous, acting corruptly in favour of pharmaceutical companies for personal popularity and profit motives. At the same time, “epistemological suspicion” or “the belief that claims to truth and knowledge are tied to particular social and material interests” (Van Zoonen, 2012, p. 56) were highly prevalent among members of Pro-vaccine choice and Stop 5G, and their visibility increased even further during T3, including in AW and 5BLs. Of course, views on experts and impostors vary from one RKC to another, but this does not limit their chances of being recognised as relevant actors and a shared resource. They can, thus, be considered to be boundary objects.

At the same time, RKC’s experts and impostors acted in reference to non-humans, i.e. first of all the virus and many pandemic objects, which allowed them to set aside their differences and shine the spotlight on their role as a useful asset in RKC strategies to refute the mainstream interpretation of the pandemic and its public social control function. From this perspective it might be said that pandemic objects acted as brokers, i.e. as actors giving RKC’s the chance to form new relationships and collectively fight the state.

8.5 The Rise of New Refused Knowledge Social Worlds in the Pandemic Arena

After the Covid-19 lockdown, Italy’s main squares crowded with public demonstrations in which the new RKC alliance’s demands for the end of the “state of emergency” (from lockdown T2 to the softening of anti-contagion laws T3, see Fig. 8.4) played out. These protests were promoted first by the so-called no-mask movement and then by the “no-green

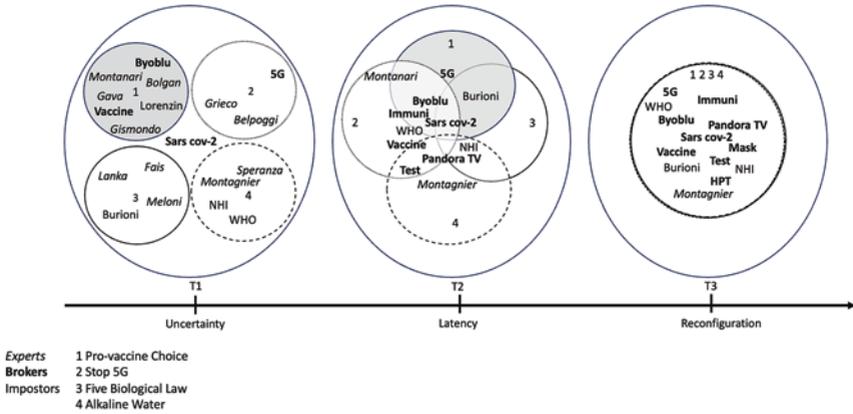


Fig. 8.4 From separate RKC to a new social world within the pandemic arena

pass⁶⁷ movement, resulting from a process which reconfigured relationships between RKC and spawned new social worlds such as R2020 (T3). As we have seen above, in fact, pandemic objects, experts and impostors played a pivotal role in building a new alliance between RKC to counteract the official version of the Covid-19 pandemic and organising dissent. These heterogeneous actors played a central role in contesting mainstream narratives and the health policy measures adopted by the government, thus fostering new opportunities for collaboration between RKC.

Burt’s (2004) “brokers” and “structural holes” concepts are of use in increasing our understanding of this reconfiguration process. Structural holes are “voids” between relational clusters (i.e. RKC in our case), whereas brokers are defined as nodes establishing new ties between these clusters, building new connections and consolidating existing relationships.

Indeed, what we observed is that initially distinct RKC (T1) began to draw closer together when the SARS CoV-2 virus and pandemic objects such as masks, Immuni, vaccines and tests progressively occupied the

⁶⁷ “Green pass” refers to the COVID-19 green certification—EU digital COVID certificate—proposed by the European Commission to facilitate the safe free movement of citizens within the European Union during the Covid-19 pandemic.

relational gaps between these social worlds (T2), opening up new windows of opportunity for both experts and impostors to enter into dialogue, even with previously unknown RKC members (Fig. 8.4). Using the broker concept to describe how pandemic objects contributed to the development of new relationships between RKC members and that of boundary objects to analyse the role played by their experts allows us to highlight the relevance of mutual entanglement between human and non-human actors within the processes that create, maintain and transform the social worlds concerned.

Therefore, on one hand, pandemic objects constituted a strategic opportunity to engage experts and impostors in responding to RKC members' needs and, on the other, they enabled various voices to be heard in public debates. In this way RKC members acquired greater visibility in the public sphere during the pandemic by reconfiguring themselves into new social worlds (T3) made up of alliances between previously distinct RKC members. The vaccine, e.g., was a powerful broker soliciting both RKC experts and impostors and triggering shared action, such as public demonstrations, online meetings and petitions, as in the following case:

A beautiful and colossal European petition for freedom of choice on vaccines, promoted by the European Forum for Vaccine Vigilance. It is very appropriate today to look at the mass of politicians in the throes of authoritarian hysteria. And if we talk about flu vaccination, anyone deciding to refuse is totally safe because there is strong scientific evidence of its ineffectiveness. (24/04/2020, Transcription and translation of a 5BLs Facebook post)

Web-platforms were also key brokers, giving great visibility to the new social worlds configured as an alliance between RKC members and their claims. While STS have highlighted the significant role played by web-platforms during public health crises (Tim et al., 2013), we also noted that they acted as brokers, both providing RKC members with alternative information during the first period of pandemic and spreading the refused knowledge supported by their experts.

Byoblu is an example of these web platforms, as an independent information channel with 511,000 subscribers until 30 March 2021, when

the channel was banned from YouTube after public accusations that it was spreading fake Covid-19 news. Byoblu’s importance during the Covid-19 controversy is also demonstrated by its increasing follower numbers. On 22 January 2020, when the Italian state of emergency was declared, Byoblu had only 7683 Instagram followers, a figure which doubled during T3 to 16,653 followers by the end of June 2020 and 518,000 on YouTube.⁷ Meanwhile, Pandora TV, another independent information channel founded in 2014 by Giulietto Chiesa, a politician and journalist, served as a refused knowledge lab with more than 100,000 subscribers. These two channels supported and disseminated the ideas of RKC experts, thereby increasing their prominence during the health emergency. For instance, Pandora TV gave the Montagnier interview on the origin of the virus that aired on 28 February 2020 great visibility, with more than 37,000 views.

Hence, Byoblu and Pandora TV gave the experts recruited by RKCs a stage, allowing them to act as facilitators or “connectors” (Cook, 2004; Latour, 1987), i.e. acting as boundary objects fostering opportunities for collaboration between RKCs. In this way, not only did experts mobilised by the virus and pandemic objects provide interpretative resources used by RKCs to reduce initial pandemic uncertainties, but they were also shared actors linking RKCs which previously acted as separate entities. Thus the combined action of pandemic objects as brokers and experts as boundary objects allowed Pro-vaccine choice, Stop 5G, AW and 5BLs to interact even more frequently and share pandemic narratives by the end of lockdown (T3).

Figure 8.5 shows the reconfiguration process which occurred after lockdown and the role played by experts, impostors and pandemic objects in greater detail. During T3 the four RKCs merged into a new social world in the pandemic arena—as an assemblage of interests and narratives—through the work of experts, pandemic objects and impostors visibly favouring coalescence between different RKCs. This new configuration can be considered an example of various processes in emerging social

⁷ One year later, on 30 March 2021, YouTube decided to close the Byoblu channel after 14 years of activity due to policy violations. Since then, Byoblu has raised more than 300,000 Euros to buy a national TV channel.

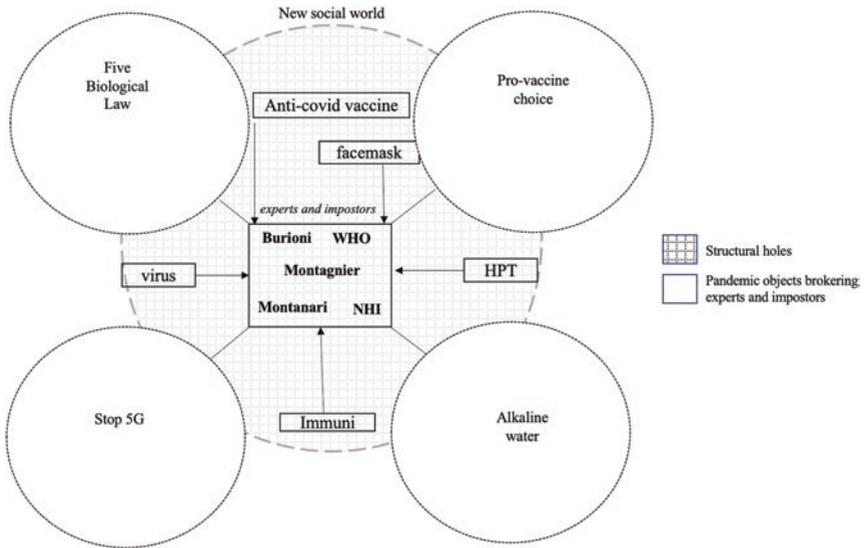


Fig. 8.5 An example of how pandemic objects trigger experts and impostors, acting as boundary objects and fostering collaboration between RKC

worlds during Covid-19, involving the RKC, as the case of the R2020 network shows. R2020 was founded by Sara Cunial, an Italian MP, and Davide Barillari, a regional councillor, both well-known supporters of the Pro-vaccine choice movement. There is nothing random about the fact that they called R2020 a “network of networks”⁸ supporting heterogeneous goals going far beyond free vaccination choice, such as alternative visions of health, with a strong emphasis on individual agency in health-related decision-making processes, home-schooling and an “awareness” lifestyle.

Collaboration between RKC trying to establish a new “regime of truth” with which to understand the pandemic crisis was made possible by mobilising their members against perceived common enemies—mainly the government and scientific institutions—thus opposing their anti-contagion strategy by supporting alternative forms of techno-scientific assemblages (Van Loon, 2002).

⁸<https://r2020.info>, (accessed: 22/05/2020).

Public demonstrations involving different RKC's were organised by R2020, including after T3, until November 2020. The main purpose of these initiatives was to oppose the Italian government's pandemic policy based on scientific experts' advice and framing the situation as a global health emergency. By contrast they demanded:

The immediate suspension of the Coronavirus state of emergency, the restoration of the Constitution and respect for our rights. We propose concrete and immediately actionable policies putting citizens' health, people's wellbeing and respect for life above all other interests. (22/05/2020, Transcription and translation from the official R2020 website: www.r2020.info)

From 30 June to 1 July 2020, R2020 organised a national event in Rome designed to recruit people and communities interested in various vaccination choice and 5G themes and refused knowledge about health in general. Several other events can be regarded as concrete expressions of the RKC reconfiguration process, such as the 20 June and 10 October "no-mask" events held in Florence and Rome, respectively. These were organised in the form of public demonstrations against the mandatory use of face masks as a danger to democracy and health (see Sect. 8.3) which were also covered by the mainstream media. Other similar local events were held in many other Italian cities—e.g. Como, Varese, Udine, Padua and Trento—occupying squares and breaking anti-contagion rules with large mask-free crowds, in the name of public rebellion. Later, new protests mobilised by pandemic objects proliferated, such as those against the green pass, which again brought together previously separate RKC's. On all these occasions a number of pandemic objects—face masks, epidemiological data and tests—acted as brokers for the sharing of interpretations elicited by RKC experts, with impostors as their counterparts.

In addition to R2020, a prominent role within the new shared RKC social world was played by the Italian Organisation for Health (OIS), founded in October 2021 with its own website and a Facebook page used by more than 10,000 people. This new social world encompasses members of Pro-vaccine choice associations together with people concerned

about 5G and/or followers of the Five Biological Laws as well as consumers of alkaline water.

New online communities challenging the mainstream view of the pandemic mushroomed. Many of these are also based on the sharing of experiential knowledge (Crabu et al., 2022; Van Zoonen, 2012), like the Telegram groups made up of individuals belonging to different RKC's and designed to monitor the side effects of vaccinations with images and descriptions of personal experiences of side-effects witnessed or heard about. Masks, Covid-19, vaccines and tests therefore provided many opportunities for RKC's to share their experts and create common lifestyle and health languages and knowledge claims consistent with alternative ideas of citizenship.

8.6 Following Pandemic Objects and Discovering New Social Worlds

Pandemic Objects, an editorial project reflecting on the objects that acquired new meanings during the pandemic, was born at London's Victoria & Albert Museum. The aim was to show how positive tests became symbols of public panic and thermometers instruments of social control, hospitals were made into convention centres, parks became contested public assets and handwritten signs began to appear in store windows around the world to explain closures or new rules, such as social distancing regulations. This project underlined the importance of objects to pandemic narratives, in both novel meanings and new uses.

What emerges from our web-ethnography during the early months of the pandemic is that some objects played a crucial role in the emergence of new social worlds within which contesting institutional knowledge has become increasingly complex: starting from a demand for alternative public health management related to Covid-19 to claiming new models of care, well-being and citizenship based on refused knowledge in pandemic times. RKC's thus coalesced into new assemblages of allies and enemies and knowledge claims combating the mainstream interpretation of the pandemic.

In fact RKC questioned the management of the pandemic by national and supranational agencies such as the Ministry of Health, the National Institute of Health and the WHO, but also the Covid-19 knowledge promulgated by these institutions and the scientists dominating the mainstream media. Some RKC experts such as Montanari and Montagnier and other institutional experts considered impostors, such as Burioni, were mobilised in a relationship with pandemic objects acting as boundary objects shared by previously separate RKCs. Re-interpretation of the virus and certain objects such as face masks, tests and apps fostered a reconfiguration of relationships between these social worlds. Separate contestations and claims became more complex, giving rise to new shared refused knowledge and public demonstrations during the early stages of the pandemic.

Although each RKC had its own set of experts, and targeted specific impostors in a critical way, the pandemic triggered new socio-technical assemblages within which such experts and impostors acted as common resources and promoted a shared language (Carlile, 2002) laying the foundations for the consolidation of new social worlds opposing science, the state, the media and corporations within the pandemic arena. Non-humans—such as the virus and certain pandemic objects—played a pivotal role in all of this not only because they became the focus of public discourse, but also because they invoked the interpretations of RKC experts together with those of impostors. From this perspective it might be said that these non-humans mobilised both experts and impostors to fill the relational gaps between RKCs which had never previously shared common goals.

Pandemic objects and the virus itself can therefore be seen as brokers capable of laying the foundations for common public demonstrations as happened in Italy, e.g., with R2020 or the “no-mask” and “no-green pass” movements which challenged the potential for herd immunity through health policy measures based on testing, face masks, green passes, apps and vaccination. New social worlds like R2020 and others, moreover, continued their work in the post-pandemic period, also extending their claims to cover multiple issues such as the global food crisis and

overbuilding.⁹ In this way the agency of pandemic objects and their role as brokers providing shared interpretative resources generated by RKC's experts and impostors, in particular, is further highlighted within refused-knowledge-based social worlds.

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⁹ See: <https://r2020.info> (last access 6 February 2023).

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9

Do the Media Refuse Refused Knowledge?

Paolo Giardullo 

9.1 Introduction

To what extent do media narratives affect the shaping of social worlds such as refused knowledge communities (RKC)? How do the traditional media contribute to keeping these separate from, and in conflict with, science? Fieldwork on four RKC cases shows that the traditional media (newspapers, TV news and their digital versions) are often accused of being the ‘in-house organs’ of the scientific elites and attacked as such. The newspapers, and the media in general, are bitterly criticised by RKC as fundamentally corrupt and for reporting only the scientific perspective and that of the political establishment underlying it (Bory et al., 2023). Evidence of this sort calls for an enquiry into the media as part of a broader analysis of RKC. Accordingly, this chapter will examine refused knowledge coverage trends and narratives across the Italian press. The

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main objective of this analysis is to consider how the media contribute to the process by which refused knowledge and its opposite, the legitimate and accepted body of scientific knowledge, are defined.

Our starting point will be the role played by the media as a key player in assuring the public role, relevance, and legitimacy of the scientific institutions and professional researchers. According to the literature, the medialisation of science is a precondition, firstly, for its legitimisation and, secondly, for the political effectiveness of scientific expertise for governments (Peters et al., 2008). In this sense, science's political value in the media is a relevant entry point, and it further supplements analysis of the social world framework to cast light on its conflict with RKC, particularly concerning the way the different social worlds are framed and constantly separated off from one another. The media are believed to be some of science's most loyal allies (Gieryn, 1999, p. 2000), and indeed, they accord wide coverage to science and technology issues. Research on science communication and scientific journalism scholarship provide evidence for this claim: on one hand, there is long-term evidence of media reporting of scientific content (Crabu et al., 2021; Summ & Volpers, 2016; Bucchi & Mazzolini, 2003; Gregory & Miller, 1998), especially biomedicine and health in general (Neresini et al., 2019). Scandals and misconduct stories (Ampollini & Bucchi, 2020), crises (Ungar, 2008), controversies (Lorenzet, 2013) and other potentially newsworthy events are undoubtedly widely covered as news stories. In addition to this interest in technoscientific topics by the media, scholars and researchers have also acknowledged that scientists and scientific/research institutions actively seek out the media spotlight (Bauer et al., 2018; Peters, 2013; Rödder et al., 2011).

The literature thus confirms that science and technology can easily be framed as connected in a symbiotic relationship with the media sphere (Besley & Nisbet, 2013; Peters et al., 2008). Taking stock of this symbiotic relationship, RKC analysis can be supplemented by considering a media-oriented research question asking specifically whether the media refuse refused knowledge and their communities. Addressing this research question can provide a more general, complementary perspective of refused knowledge studies and an alternative entry point such as this may complement the analysis of social worlds which polarise refused

knowledge and science. RKC's take part in a network of interactions in which they feel they belong to a 'social world', and the opposite is also true: scientific institutions like to feel part of different social worlds from those of RKC's. Thus, both sides believe the other to be wrong or, at best, biased. This supposed wrongness is also built, negotiated, and shaped through communication flows across the media, a process which can be interpreted as boundary work: RKC's self-identify as providers of alternative epistemologies making claims about health and citizenship (Morsello & Giardullo, 2022; Crabu et al., 2022).

In this general context, the (social) media play a significant role within the ecology of resources mobilised by RKC's, and media narratives perform an active role in shaping identity and supporting RKC's' discourses in the four cases analysed in this book (Bory et al., 2023). Digital ethnography shows that RKC experts act as influencers and thus catalyse (read accelerate) certain processes precisely through discursive practices identifying boundaries between communities: RKC's and scientific institutions (Ibid.). By claiming the epistemic validity of experiential knowledge through a repertoire of practices this identity-shaping process is explored widely and analytically throughout this book. Complementing this outlook requires exploring the flip side of the coin: how the media actively strengthen and politically legitimise science when they talk about refused knowledge.

As we will see in the following sections, both coverage and discourses embody a performative role that can be regarded as an element in boundary work contributing to separating RKC's and social worlds situated within the scientific universe of discourse. In this case, the relationship between the two seems complementary: RKC discourses would not exist without their counterparts, the health institutions and scientific experts. In this case, enquiring into the way separation between social worlds takes place encompasses the media domain, offering a supplementary outlook: who and what is accepted as scientific and, conversely, who and what is not.

Within this general context, I will analyse both the coverage of the four RKC's and the related narratives using the *Technoscientific Issue in the*

Public Sphere (TIPS¹) project platform. Rather than contributing to the analysis of each single case, the analysis aims to offer a broader view of the role of the media, namely the daily press, as regards refused knowledge in general. This analysis presents several implications addressed using a two-fold approach. Indeed, its examination of the quantitative presence of RKC in the media adopts a specific concept from media analysis, agenda-cutting, i.e. the omission of specific issues (Buchmeier, 2020). In addition to this coverage analysis, I will also examine the content of the articles related to the RKC at the core of this book. The framing and narratives characterising the discourses around RKC has the potential to enrich our understanding of the boundary definition and social world separation processes. Further analytical resources have been borrowed from media studies and communication scholarship, specifically from analysis of conspiracy theories, fake news, and debunking practices, often examined in new media, and on cases of pseudoscience and fraud. These accounts can offer a specific perspective on the main research question addressed here. Given the uneven distribution of coverage of the four RKC, I compared their framing and the features with other publicly contested and ostracised scientific claims and discoveries, such as the ‘Di Bella method’ and the ‘Stamina Protocol’ controversies.² To this end, the analysis considers a long-term timespan covering a period from 2010 to 2022 enabling comparison across time between the four RKC and their benchmark corpus contents.

Before moving on to the analysis, I will address the specific contribution of the media to reinforcing science’s authority. Evidence from the literature, as we will see, is made up of a nexus between the quantitative coverage dimension and the qualitative dimension regarding the narrative adopted in newspaper articles. Coherently, the analysis reports that

¹ <http://www.tipsproject.eu/tips/#/public/home>.

² The ‘Di Bella method’ and the ‘Stamina Protocol’ are two cases of medical fraud that drove media attention in Italy. The former had its momentum around 1997–1998 and was about a supposedly miraculous cure for spinal muscular atrophy as claimed by its inventor Dr Luigi Bella, a physician. The latter was about the opportunity to cure neurodegenerative diseases through stem cells; it was promoted by Davide Vannoni, a communication expert, in between 2009 and 2013. Both cases raised some popular consensus pushing health authorities in Italy to start an experimentation that eventually failed. ‘Di Bella method’ and ‘Stamina Protocol’ as discussed in Sect. 9.3 will be used as benchmarks for the analysis of media narratives of RKC under scrutiny.

both the coverage and the content vary from one case to another on the grounds of specific media style, in particular, as a representative of the media, the newspapers sometimes reject some RKC's more strenuously than others.

9.2 Public Communication of Science and Technology: Some of the Lessons Learned About Institutionalisation Trajectories via the Media

Interactions between journalists and scientists are frequent and eased by long-term contact. While research institutions and press offices play a significant role in the public communication of science (Peters et al., 2008), scientists and researchers learn about their colleagues through the mass media (Rödger, 2009). This state of affairs has prompted scholars to consider the public communication of science a functional necessity and a global phenomenon in democratic knowledge societies (Peters et al., 2008). The relationship between scientific research and media communication can be characterised by means of the media's twofold role: institutionalising the official research populating emerging innovation networks (Gibbons et al., 1994) and promoting a critical approach to science. These flip sides of the same coin are key to the symbiotic relationship existing between science and the media.

In exploring the key features of this relationship, we will examine past public communication of science trajectories and their narratives, as a feature of modern science since the early nineteenth century, taking a number of forms from itinerant lectures demonstrating scientific principles common in the United States (Lewenstein, 2016) to the public demonstrations widespread around Europe (Jackson, 2016). Scientists in France and Italy have long been writing for non-specialist audiences about astronomy and physics (Bucchi & Trench, 2014), but it was not until the early twentieth century that the people involved in public communication of science and technology, such as science journalists, became visible and their professional credentials publicly established. Two

features of the well-known deficit model of public communication of science have since developed and certain communicative patterns are still visible today: the need to inform audiences of recent developments in technoscientific research, assuming a knowledge transfer need, with such transfer needing to be tailored to the (hypothetical) requirements of a passive audience with (uniformly) limited, if any, ability to grasp its scientific contents. While this model would appear seriously limited, even inadequate, it has historically been a success story: downstream communication simplifying content for audiences (Hetland, 2014) is a rhetorical trait typical of science's public image across the news (Dunwoody, 2014) and seems to transcend varying innovation and scientific research regimes (e.g. the change from Mode 1 to Mode 2, Gibbons et al., 1994). Although it is generally agreed that diverse communication models may coexist, longitudinal examples of media analysis have recorded a trend to a specific kind of 'knowledge transfer' rhetoric. The prominence of this perspective is suffused by a key audience knowledge deficit assumption requiring knowledge transfer not only to inform—as with any content becoming news—but also to educate audiences.

This perspective gained momentum after World War Two with massive and structured funding for scientific research from national governments, the so-called social contract for science (Guston, 2000). Long-term analysis of science coverage in newspapers confirms increased attention to scientific content, at least until the early 2000s (Bauer, 2012; Pansegrau & Bauer, 2018) and subsequently remaining stable (Neresini, 2017).

In terms of narratives, a number of studies have noted a tendency to celebrate science and its role: from a diffusionist perspective of innovation, science is portrayed as a major force in steering innovation and thus generating well-being. A seminal work by Dorothy Nelkin for the US context (1996) highlighted a media portrayal of scientists as gifted problem-solvers, thus cultivating an image of science and research as a major tool for successfully addressing social needs. Bucchi and Mazzolini (2003) reported similar findings in the Italian context, with a tendency to represent science as uncontroversial and narratives depicting scientists and news with a problem-solving orientation, generally in neutral tones. Other researchers have confirmed this finding regarding the use of

promotional metaphors in stem cell research and the potential application of new genetic technologies (Rödder & Schaffer, 2010).

Schäfer (2011) called this narrative register ‘popularisation mode’, in accordance with what we have referred to as knowledge transfer. Such articles are frequently published in special sections and a scientific coverage boom, first in physics and then in health and biomedicine, was supported by this kind of narrative (Neresini & Lorenzet, 2019). Although scientists may criticise scientific journalism for being over simplistic and inaccurate, even sensationalist and alarmist, paying little attention to specific details such as experimental design (Dudo, 2015), this kind of narrative reflects a supposedly aseptic communication mode simplifying a register used among scientists themselves (Schäfer, 2011). An explanation for this may be found in the features of the medialisation process (31). To build public political legitimacy and successfully apply for funding, scientific research institutions (labs and universities and also firms) align to this media logic, increasingly equipping themselves with special facilities (i.e. press offices) with which to provide content for journals and other media outlets (Schäfer, 2011).

A different means by which media report news about science and research consists of scientific topics discussions going beyond merely summarising research/expert findings or tackling the role of scientific research in connection with broader issues (Summ & Volpers, 2016). Indeed, it is sometimes its political value which brings scientific content into the public debate, as with energy transition (Neresini et al., 2020), nuclear energy (Tollefson, 2020; Gamson & Modigliani, 1989), and other environmental crisis topics, such as climate change (Boykoff & Boykoff, 2007) and, more recently, the SARS-CoV-2 pandemic (Crabu et al., 2021).

This review shows that a twofold science reporting style such as this is homogeneously distributed across media outlets and cultural contexts. Coverage and celebrative rhetoric would seem to be constant across a range of countries, but what happens when the content of the topic is controversial, unproven, or even supposedly false, like refused knowledge? Recent scholarship has examined fake news and misinformation, for a better informed analysis of the treatment of refused knowledge in the media.

9.3 Alternative Knowledge in the Public Domain

Over this last decade, many science communication scholars have tackled the issue of fake news (Vargo et al., 2018) and misinformation (Wagner & Boczkowsky, 2019), including in connection with the concept of post-truth (Iyengar & Massey, 2019). Most, if not the entire, literature published on the issue has concentrated on the way content is shared, consumed, and, ultimately, circulated via social media, in an attempt to detect and gauge effects on its audience. On the strength of digital methods, scholars have tracked the dissemination of content across users' profiles, reconstructing networks of users coalescing around specific issues and generating what have been called echo chambers (Del Vicario et al., 2016). Although the fake news topic is not directly connected with the research presented in this book (see Introduction and Chap. 2 by Federico Neresini), a number of insights can, in any case, be distilled from analysing refused knowledge in public. Indeed, social worlds can be set up on the basis of the discourse disseminated by the media. As new media studies and internet studies have pointed out, media technologies, and more specifically ICTs, contribute to holding together social worlds (Maxigas & Latzko-Toth, 2020) which cross territorial boundaries (Couldry & Hepp, 2013). In the case of RKC, the role of influencers channelling content and counter-narratives helped to hold together groups and communities across Italy during the first year of the pandemic (Bory et al., 2023).

Echo chambers, and social bubbles, can be considered a relevant online example, consistent with the social worlds framework. In addition to media practices, specific content may also reinforce world views and then configure the separation of social worlds. Transposing these processes to the specific context of newspapers, more specifically, can provide insights into this same social world separation process. Indeed, the media offer a rhetorical set of images, metaphors, and labels for 'knowledge transfer', contributing to the institutionalisation of scientific research. As we saw in Sect. 9.2 of this chapter which outlined the main features of the 'regular narratives' contributing to building science as a separate social world

while opposing complementary RKC narrative frameworks. Currently, we are lacking a similar account of the general features of narratives on issues publicly marked as non-science, a fact which is particularly striking if we consider the well-known example of fringe science in the case of cold fusion. In this example a news outlet provided a narrative on Pons and Fleischman that leveraged a successful experiment rhetoric and mobilised resources for the two, including listing their scientific credentials (Gieryn, 1999). Only once Pons and Fleischman's public example had been disavowed did the media report it as a hoax, changing the tone and register used in relation to the two researchers.

Hence, to properly answer our main research question, investigating the narratives produced by the media may further inform this chapter's analysis. As the Pons and Fleischman example showed, the media are fully capable of endorsing and rejecting news at will, on the basis of what they consider true or fake. The cold fusion story also demonstrated media willingness to adapt their narratives about a single object and frame it in contrasting ways. To better understand whether, how, and to what extent the media refuse refused knowledge, I will first reconstruct features of two relevant Italian cases: the 'Stamina Protocol' and the 'Di Bella method'. Currently, these are closed controversies: both have been labelled fraud³ and non-science (Abbott, 2013), respectively, in the public debate, and accordingly disparaged.⁴ For this reason, the two cases constitute a benchmark with which to compare the framing of refused knowledge, casting light on the ways in which traditional media outlets rhetorically reject RKCs by marking the difference between what is accepted as a science and what is not. This can be viewed as a form of public discrediting, but the two cases are in any case benchmarks for interpretations of media coverage of the four RKCs examined here.

³The titles and texts of articles published in the Italian newspapers reported from here onwards have been translated into English by the author. "The country of saints and navigators [i.e. Italy, ed.] is now packed with misunderstood genius", published in *Il Giornale*, 24 June 2013; "Nature [the journal, ed.] against Stamina 'It should be stopped'" published in *La Repubblica*, 13 December 2013; "The Stamina method is a scientific fraud which endangers our health", published in *La Stampa*, 16 June 2015.

⁴"Charlatans in science", published on *Sole-24Ore*, 26 March 2018.

Working on content and narrative is crucial, but a further interesting line of analysis consists of the coverage of specific issues over time. Vargo et al. (2018) tracked the connection between issues at the core of fake news narratives, typically disseminated online, and the coverage of these same issues on other news outlets. Their research reveals a kind of agenda-setting effect derived from fake news creators propagating mainly across other online sources. Traditional media, such as newspapers (Ibid.), tend not to be influenced by so-called fake news providers. If they cover such issues, it is more likely to be part of a full-blown debunking campaign. Traditional news sources, such as the BBC for instance (Jackson, 2017), may be openly committed to combating fake news through debunking, but most media outlets, especially quality newspapers, avoid reporting them (Vargo et al., 2018). The hypothetical lack of coverage of RKC's can be explored by surveying newspaper coverage: low coverage by quality newspaper outlets about a certain issue would indeed indicate a certain degree of refusal. Buchmeier called this agenda-cutting (Buchmeier, 2020).⁵ Connected to the parent theory of agenda-setting, agenda-cutting is not merely its opposite, namely an absence of coverage, but rather entails the specific reasons why media do not cover a specific issue (issue-omission) or, rather, prefer to rank it low in their agendas (issue-diminution) or even, in the long term, stop covering it (issue-removal). This perspective complements the idea of the media's carrying capacity (Hilgartner & Bosk, 1988), according to which issues compete for inclusion in the media agenda over time. They succeed in this under certain conditions, such as when they can be related to other news stories (Neresini, 2000) or meet some relevance parameters (e.g. proximity, recency) that connect with audience interests (Scheufele, 2010) and thus become anchored (Giardullo, 2019). The concept of agenda-cutting enables us to analytically distinguish between different cases and explore hypotheses seeing the media as a primary supporter of science institutionalisation by omitting, diminishing, or even removing specific issues.

⁵The concept emerged well before Buchmeier's contribution but, until recently, it was undertheorised in media and journalistic studies. Moreover, as Buchmeier himself noted, although some scholars may have described or analysed omission, diminution or removal processes in the media they rarely made any reference to the concept of agenda-cutting.

In sum, the method adopted for the analysis combines the two approaches described so far (Table 9.1).

The analysis that follows builds on two main empirical approaches. The first is a quantitative approach that assesses topics' absence/presence or visibility/invisibility, thus indicating a primary level of rejection of refused knowledge. This is further informed by topic modelling (Blei et al., 2003) and contributes to characterising coverage by interpreting the agenda-cutting process. In the second approach, qualitative analysis identifies a secondary rejection level made apparent by means of openly discrediting/crediting such knowledge and the related social worlds, thus informing and qualifying the agenda-cutting process. For Buchmeier (2020, p. 4), performing an agenda-cutting analysis requires contrasting or comparing the absence of coverage (and how it may reduce over time) with some other evidence. Thus, researchers must be aware that something is happening if they are to ensure that a topic is not covered.

Thus, our data source was the TIPS project (Neresini et al., 2020, 2023; Crabu et al., 2021), informed by the research experience of the team that worked for an extended period on the four RKC. The TIPS project developed a purposed platform as a tool with which to survey the Italian media sphere by monitoring major daily newspapers. The platform offers a complete database of articles published since 2010 by the main Italian daily newspapers which allowed us to survey a significant share of the Italian media in a longitudinal way, in both coverage and article content terms. However, as we will see below, the two approaches tend to conflate, since some of the narratives are not independent of the coverage. Building upon the data provided by TIPS and comparing it with the analysis previously published by the research group, these two enquiry approaches analytically tackle the main research question regarding the role of the media in separating social worlds and verify the institutionalisation of science through media coverage and discourse hypothesis.

Table 9.1 Methodological approaches to uncovering media processes related to newspaper refused knowledge discourses and the related communities

Approach	Unit of analysis	Object	Process
Quantitative	Articles	Coverage and topic modelling	Agenda-cutting
Qualitative	Words	Narratives and framing	Discrediting

9.4 Refused Knowledge Communities in Italian Daily Newspapers: Coverage

To assess the presence of an ongoing agenda-cutting process, a query design procedure was implemented. The queries were based on the objects at the core of the four RKC: vaccination, five biological laws, 5G technology, and alkaline water. These objects were then matched with further keywords that emerged from the fieldwork by the research team. The outputs of this procedure consist of articles reporting on the issues and do not necessarily represent the four RKC. This is thus a dataset of use in understanding the narratives generated by sources other than the community itself. If coverage of the issues related to the four RKC at the core of this book are considered, it seems clear that they have been covered to entirely different degrees. Table 9.2 shows the queries used to extract the articles for the four RKC.

The differences in coverage between the four RKC are evident, but this is even more interesting if we examine distribution over time. Indeed, the time variable did not affect the coverage of the four RKC in the same way. Most of the research underlying this book was done during the pandemic, and three out of the four communities were in some way favoured by lockdown, and increased their supporter (Morsello & Giardullo, 2022; Bory et al., 2023) and even practitioner numbers (Crabu et al., 2022). The same was not true of the Italian daily newspapers. The impact was extremely low for articles that the four queries generated, if they are

Table 9.2 Number of articles for coverage and narrative analysis (2010–2022)

RKC	Query	Number of articles retrieved
Pro-vaccine choice ^a	+(‘free vax’ ‘no vax’ ‘no-vax’)+ vaccin*	8145
5BLs	‘metodo hamer’ ‘cinque leggi biologiche’ ‘5BL’ ‘nuova medicina germanica’	70
Stop-5G	(elettrosensibil* +5g) (‘No-5g’)	28
Alkaline water	‘acqua alcalina’ ‘dieta alcalina’ ‘benessere alcalino’	14

Source: Author’s own elaboration of TIPS project’s data

^aFor this case a broader query was launched: ‘vaccin*’, cf. below

compared with the total number of published articles over the same period. Alkaline water and Stop-5G issues were virtually absent from the media debate (with 0.0004% and 0.0006%, respectively, on average, from 2010 to 2022), while 5BLs' presence was higher, with an impact of about 0.0023%. These three RKC's were rarely reported in the news. Considering the growing number of social media users (Bory et al., 2023) only following content and the accounts of influencers related to these issues, or directly engaged in communities, an ongoing agenda-cutting process seems clear. Although relevant differences between the three communities do exist (see further details in the next section), the issues at stake were omitted to an almost equal extent. Considering variable time, by year, it was noticeable that although alkaline water was almost entirely omitted, 5BLs and Stop-5G coverage peaked in 2016 and 2020, respectively.⁶ After these peaks, coverage decreased markedly, dropping by more than half for 5BLs and almost entirely vanishing for Stop-5G. It must thus be inferred that a twofold agenda-cutting process was under way: the low coverage hints at issue-omission, as in the case of alkaline water, but this was further exacerbated by what may have been issue-removal by Italian newspapers for more controversial issues such as 5BLs and Stop-5G, which imply serious health risks and long-lasting debate and controversy over electro-sensitivity.

The pro-vaccine choice issue shows a completely different pattern: coverage was incomparably higher and definitely more constant over time (total articles published = 0.225% in the 2010–2022 period and 0.49% in 2017–2022), peaking at 5214 articles in 2021 (1.17% impact). For this case, it would seem to be hard even to consider an agenda-cutting hypothesis, both by comparing the pro-vaccine choice data to other issues and also in absolute terms. If time is taken into account, coverage can be observed to have increased after 2017 (Fig. 9.1).

The news articles reported vaccines and vaccination (2010–2016, N = 3627) as a medical resource and immunisation of subjects

⁶Peaks for the two RKC's issued considered are very small and limited across time: 24 articles for 5BLs in 2013, 14 articles in 2019 for Stop-5G.

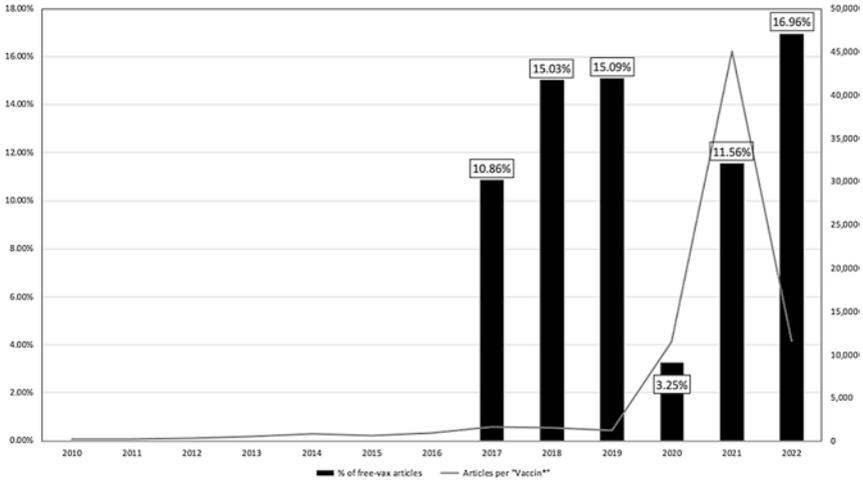


Fig. 9.1 Comparing trends: percentage of articles about the pro-vaccine choice RKC (black bars left hand scale) out of the total of vaccine-related articles (query 'vaccin*' N= 76,182, grey line right hand scale). (Source: Author's own elaboration of TIPS project's data)

potentially at risk, as in the case of new vaccines against meningitis⁷ and AIDS.⁸ This seems to support the celebrative science narrative. Although some articles about vaccine adverse reactions are sporadically to be found, these were mainly framed as cases of medical malpractice.⁹ In general, vaccination hesitancy was not on the agenda nor were the RKC. A marked increase in articles published during the pandemic years, especially from late 2020 onwards, was visible with numbers of articles doubling from 2019 to 2020 (from 179 to 373 articles) and further increasing thirteen-fold in 2021 (5194 articles). Looking at this data from an anchoring perspective (Giardullo, 2019) we might conclude that pro-vaccine choice received more coverage precisely because of the well-known COVID-19 vaccine controversy, the so-called AstraZeneca

⁷“A breakthrough vaccine prevents meningitis”, published in *Il Giornale*, 14 July 2013.

⁸“AIDS, Italian vaccine effective: the TAT supports antibody production”, published in *Il Messaggero*, 29 April 2015.

⁹“Our sister killed by a vaccine she should not have had”, published in *La Stampa*, 20 February 2013. In this case, according to articles reporting the victim's family's words, the physician gave her a jab even though she was ill, with flu symptoms.

Controversy (Sendra et al., 2023). Similarly, the pro-vaccine choice issue was included in the agenda more frequently because of restrictions on the non-vaxed designed to raise vaccination rates. As soon as restrictions on individual mobility and social distancing began to be lifted, the public relevance threshold was crossed. Indeed, a previous study found that protests in the country were often organised by supporters of pro-vaccine choice, with 28.6% of the rally and protest event total coinciding with the advent of vaccination campaigns in Italy and involving pro-vaccine choice groups (Della Porta & Lavizzari, 2022). The ‘no-vax’ label began being used widely in 2017 and prior to this no articles were published with this label in any of the eight daily newspapers monitored by the TIPS project. Although, historically, opposition to mandatory public vaccination is as old as vaccination policies themselves, this label emerged only in 2017, the year of great mobilisation against mandatory paediatric vaccinations in Italy, defined by the so-called Decreto Lorenzin approved in 2016. The reasons for this label are perhaps tracked in accordance with the ‘No-Movement’ brand, used as shorthand for local unwanted land use (LULU) movements (Bertuzzi, 2019).

Relevant indications for agenda-cutting analysis may emerge from a comparison of percentage trends for articles about pro-vaccine choice as a proportion of article totals on the subject of vaccines: there was considerable reference to pro-vaccine choice communities during the years of greatest mobilisation (2017–2019), during which research showed that the community reorganised and its political relevance increased as politicians brought the issue to the Italian Parliament (Bory et al., 2023; Morsello & Giardullo, 2022; Casula & Toth, 2018). On average, 13.66% of articles referring to vaccines reported pro-vaccine choice in a growing common trend. Interestingly, in the pandemic years (2020–2022), the two trends decoupled: a rapid growth in the number of articles about vaccines was not matched by articles about pro-vaccine choice (only 3.5%), while the political and scientific debate about the pandemic ramped up in the Italian press (Crabu et al., 2021). In 2021, the peak coverage of vaccines accounted for 15% of all articles published by newspapers monitored by TIPS. However, the share of articles about pro-vaccine choice was lower (11.56%) than the 2017–2019 period (average is 13.66%). In 2022, vaccine related article numbers dropped, whilst the

pro-vaccine choice article share peaked at close to 17%. Based on these figures, we might conclude that an agenda-cutting process took place during the gloomiest period of the pandemic, a period of great uncertainty during which most hopes were pinned on those working on vaccine technology development. If we apply Buchmeier's categorisation, such a decoupling of trends might indicate that some sort of issue-removal lasted right through 2020. There might be various reasons why the newspapers reduced coverage of pro-vaccine choice issues: a sense of responsibility, recommendations on limiting dispute and controversy during the critical phase of the pandemic, etc. The above data shows an agenda-cutting process that changed in 2021 and possibly even evolved into a new pattern in 2022.

Considering the full range of RKC cases under scrutiny, we might hypothesise that the agenda-cutting process did not apply equally to all four RKC. In the case of the pro-vaccine choice issue, it would even seem to work differently for the same issue in accordance with events. Attempting to characterise the four RKC, the time variable allowed some specific interpretation to be brought in, but it was content analysis which fleshed out the answer to our question about media coverage of refused knowledge.

9.5 Between Institutionalisation and Discrediting: Keeping Social Worlds Apart Discursively

While long-term trends in the public communication of science show that media outlets are frequently celebrative of research progress and success, according special value to experiment outcomes and reporting scientific papers, the media also pay particular attention to controversial cases. Public controversies in the media often highlight clashes between different actors, anchoring them to pre-existing political debates, as we have seen. Scandals and misconduct stories (Ampollini & Bucchi, 2020) are potentially newsworthy stories, but it is interesting to note that they are widely covered as news stories. What about the way certain topics are

framed? The contributions in this book have noted that mutual accusations of untrustworthiness are very frequent and criticisms are directed at methods (Morsello & Giardullo, 2022; Bory et al., 2023), conspiracies (Bory et al., 2023; Stop-5G, this book), and epistemic assumptions (Bory et al., 2023; Stop-5G and alkaline water, this book). Accusation and blaming are recurrent, but do they culminate in open public discrediting? This latter was reported, for instance, in analysis of the framing of protesters (Chen, 2019): in Canada, a grassroots movement of indigenous people against the implementation of looser environmental regulations was discredited publicly on the media through a denigration strategy against its leadership (Ibid., p. 149). Similar framing emerged for the two benchmark cases: ‘Stamina Protocol’ and the ‘Di Bella method’. Analysing the vocabulary characterising the articles about these two cases (N = 873) over 13 years (2010–2022), key elements emerge such as the use of specific terms such as ‘ciarlatano’ (quack) and ‘guru’ for Davide Vannoni and Luigi Di Bella, the two exponents of supposedly miraculous cures for spinal muscular atrophy, oncological as well as neurodegenerative diseases. Interestingly, for the benchmark corpus about the ‘Stamina Protocol’ and ‘Di Bella method’ cases, a trajectory by which they went from being portrayed as apparently miraculous therapeutic cures to hoaxes is observable. Indeed, both therapies were imposed on hospitals by ministerial decrees or by administrative courts as patient-demand-prompted experiments supported by the media.¹⁰

These discourses demonstrate an extremely negative media tone indicative of marked scepticism. I have already discussed the highly negative framing of the two cases, as well as the use of epistemic authorities outside the newspapers to reinstate the scientific community’s public image, such as the presence of influential journals (e.g. *Nature*), or celebrities from the world of biomedical research, such as famous researcher and senator Elena Cattaneo. In these cases, not only did the epistemic

¹⁰ Stamina protocol was a highly emotive issue as its patients were children suffering from muscular dystrophies. “*Little Sofia may be cured*”, published on *Il Mattino di Napoli*, 8 June 2013; “Stamina protocol, approved for Federico: judges give green light for the therapy”, published in *La Repubblica*, 18 March 2013. Similarly some journalists endorsed parents’ point of view and expressed their support for the protocol and the hope it offered, as in this case “Stamina, the rage and the cure, open letter to Minister Lorenzin” <https://blog.ilgiornale.it/locati/2013/07/04/la-rabbia-e-la-cura-lettera-al-ministro-lorenzin/> retrieved on 28 January 2023.

authorities move to limit the damage done by ‘quacks’ but they may also have worked to restore the scientific community’s reputation.

‘If in cases of scientific fraud Italy should develop serious restrictive measures, in cases of research excellence it is important that it increases funding and attention to science. In the light of the challenging conditions in which excellence emerges, I have been disappointed by the lack of interest and, dare I say it, the lack of competence shown by recent governments towards biomedical innovations’. This is explained by Alison Abbott, a long-standing author for the most celebrated scientific journal, *Nature*. (*La Stampa*, 15 April 2015)

The Stamina affair could become a new ‘Di Bella’ case: this is the concern expressed today by leading international stem cell experts, gathered at the Telethon conference taking place in Riva del Garda (Trento). [...] ‘Science—added Naldini—has set itself rules for clinical trials, to guarantee patient safety and research. Leaving the rules behind means jeopardising patients’ health and risking failing to see the potential effectiveness of the therapy. ‘It is not a matter of thinking one way or the other, but of looking for evidence,’ added Elena Cattaneo. In the case of the Stamina method, there is no evidence. This way of proceeding,’ he concluded, ‘is the antithesis of our usual working method’. (*La Repubblica*, 11 March 2013)

This narrative was designed to restore a scientific reputation tainted by full-blown hoaxes (the ‘Di Bella method’) or potentially new and as yet unproven methods (‘Stamina Protocol’). Can similar processes be detected for the issues related to the four RKC’s under scrutiny?

The four RKC issues are so heterogeneous that the narratives and rhetorical strategies marshalled by newspapers to frame these issues differed. To start with, analysis of the way these issues were framed clearly showed the primacy of the deviance frame in articles about 5BLs:

Against the defendant, the order (medical association) will also ask for compensation for damage to the decorum of the medical profession. The note sent by the organisation states that ‘by practising and spreading Hamer’s German New Medicine, Dr Germana Durando has discredited

the profession, adding to the very serious damage done to the patient who has been deprived of the care of official medicine and treatment of recognised effectiveness'. 'Unconventional medicine,' explains President Guido Giustetto, 'is complementary, not a substitute, for official medicine, as Article 15 of the Code of Medical Ethics clearly states. In addition, and this is the central aspect of the issue, the doctor must not remove the person being treated from scientifically founded treatment of proven efficacy and is therefore obliged to decide in good time when it is appropriate to discontinue any unconventional methods adopted and resort to official medicine, so as to guarantee the patient the most suitable conditions of safety and efficacy of treatment'. (*La Stampa*, 22 April 2016)

Who was Geerd Hamer? For medicine and the judiciary in many European countries, he was a quack, a dangerous pied piper who persuaded cancer patients to treat themselves with remedies that were not at all scientific, refusing surgery and chemotherapy, even in cases where there was a good chance of a cure. To his followers, including certain doctors, he was a persecuted prophet. He was soon struck off the medical register in Germany (in 1986), and in other countries, including Norway, where he took refuge and founded a university in 2010 in his house on the outskirts of Sandefjord. [...] What makes his theory denying the medicinal effects of chemotherapy clearly delusional—and, unfortunately, it must be said, more viral—is his attack on medicine, which he considered traditional and accused of being a Jewish conspiracy. On the German New Medicine website, he published a letter to Trump, in which he accused Jewish rabbis and doctors of saving their own people with the Hamer cure and using chemotherapy and administering morphine to kill non-Jews. (*Corriere della Sera*, 5 July 2017)

The two excerpts above show a deviance frame clearly supported by reference to victims who have turned to people following the dictates of the 5BLs. Many such cases include physicians or naturopaths whose patients died because they refused medical cures.¹¹ The deviance frame is further supported by some institutions, such as the Italian Medical

¹¹“Refuses treatment because follower of Hamer Method, another woman died in Rimini”, published in *Corriere della Sera* 3 March 2016; “Eleonora Bottaro, parents sentenced to two years in prison because they made her refuse treatment”, published in *La Repubblica*, 20 June 2019; “Manslaughter accusation for the doctor who endorsed his colleague’s decision to treat melanoma with homeopathy”, published in *Il Sole-24Ore*, 15 February 2022.

Association, which require physicians to follow ethical rules. In this sense, the frame is strong and cohesive and fits into a crime news framework. 5BLs disciples are also contextualised as examples of extremely dangerous individuals frequently compared to Vannoni and Di Bella, labelled witch doctors in search of patients to cheat.¹² In the case of public controversies about technoscientific issues false balance is commonly found¹³ in media reports; presenting opposing positions on a certain issue in the same way gives an erroneous impression of scientific uncertainty. This does not happen since there is agreement among scientists and across the media as well: the benchmarking cases would seem to suggest that when the scientific community unanimously labels a theory or approach deviant, the media tend to follow suit.

However, this is not the case for pro-vaccine choice where, besides reports of protests, a recurrent theme in the articles is blaming and stigmatising those against compulsory vaccinations. A subject which was less present during the 2017–2019 period, many stories were about people who had been hospitalised or died from diseases that could have been prevented by vaccines. This emerged strongly during the pandemic period as a recurring topic.¹⁴ Although deaths of no-vaxers were not celebrated, newspaper articles tended to report such news together with a call for vaccination by health authorities. The blaming frame would seem to be a sort of hidden flip side of the coin, appealing for responsible social communication campaigns and typically triggering fear as a persuasion strategy.

The Stop-5G narrative is different again: there are very few articles in the corpus and they are divided up into two groups: a small one relating

¹²“Alternative cures, urine and scorpion venom: this is how the latest witch doctors recruit patients on the web”, published in *La Repubblica*, 2 February 2016.

¹³According to Dixon and Clarke (2013) “while balance is considered a prominent journalistic norm (...), ‘false balance’ occurs when a perspective supported by an overwhelming amount of evidence is presented alongside others with less/no support and context—where the strength of evidence lies—is excluded (...) (pp. 359).

¹⁴“No vax killed by Covid at 62. He used to say: I am the last of the Native Americans”, published in *Il Mattino di Napoli*, 5 February 2022; “Ten-year-old child died from Covid: he was hospitalised at Bambin Gesù. Call for vaccination”, published in *Il Messaggero*, 12 February 2022.

to examples of local authorities diffident about 5G experimentation,¹⁵ and another group about the Stop-5G activists within the broader wave of protests against mobility restrictions and social mobility limitations in the summer of 2020.

On the railings delimiting the space around Dante's statue, signs were posted: 'Doctors and journalists, be dignified, tell the truth', 'It's not a pandemic, it's genocide', 'Deaths counted twice deserve riots', 'Autopsies forbidden, people killed', 'Your health care devastated, our freedom humiliated', are some of the slogans. Some brought carnival masks to mock wearing surgical or cloth ones. Among the demonstrators' placards was also one with the inscription 'No 5G'. (*Mattino di Napoli*, 11 July 2020)

I swear, it's all true! [...] Two other former 'grillini' [members of the 5 Star political party], Sara Cunial and Davide Barillari, have founded Vita, which, among other things, is Stop-5G and brings together the Mothers' People, the Sentinels of Liberty and other valiant people (...). Excuse me, but I've got a terrible headache: I'm going to get a vaccine. (*La Stampa*, 4 August 2022)

Taken together, these excerpts echo other analyses showing the way the Stop-5G RKC's were politicised in a drift towards a broader conspiracy-oriented attitude (Bory et al., 2023). It should be noted that the second excerpt betrays an ironic take on a political proposal that united RKC's. Although not widely reported in the press, it is a further perspective on RKC's that not infrequently supplements attempts at debunking.¹⁶

In the case of alkaline water, within a general context of virtually non-existent coverage, framing alternated between a presentation as perfectly normalised and fashionable to a more debatable one.

A more effective and costly option is a system which originated in Japan and is spreading throughout the world which consists of additional cleans-

¹⁵"Sagliano, 500 ask to stop 5G experimentation", published in *La Stampa*, February 2020; "Reggio Calabria 'stop 5G' During Covid municipalities against antennas skyrocketed" published in *Corriere della Sera*, 7 July 2020.

¹⁶"Pendants "against" 5G, actually radioactive: Dutch authorities ban 10 products", published in *Corriere della Sera*, 20 December 2021.

ing and sanitising action, a highly effective method that oxygenates and energises water, making it alkaline. Alkaline water thoroughly counteracts free radicals, pollution and stress in our organisms. (*Sole-24 ore*, 29 January 2015)

Initially presented as a promising natural adjuvant for stress and even cancer prevention supported by examples of national celebrities making alkaline water palatable,¹⁷ more recently, the framing has shifted towards debunking, following the same path as reported for other cases in the literature (Vargo et al., 2018).

Prof. Conte makes no bones about the fact that when it comes to the benefits of alkaline water, the nonsense is piled up out of all proportion. If we ask whether alkaline water is good or bad for us, we have to answer that it is neither good nor bad for us. This is another hoax. [...] In fact, since it was discovered that areas surrounding some tumour tissues have an acidic pH value, the idea has been to do business by driving people to alkalise their bodies. In this regard, it is estimated that per capita water consumption is equivalent to 206 litres per year in bottled form, which translates into a turnover of 10 billion. (*Sole-24 ore*, 3 December 2018)

In this case the debunking is by experts interviewed to explain why alkaline water is not as promising as some sellers argue.

So, Joshua McAdams and Taylor BlandBall, arbitrarily decided to give their son Noah, who suffers from lymphoblastic leukaemia, a mix of CBD (an acronym for cannabidiol) oils, fresh food and alkaline water, and refuse traditional chemotherapy treatments. According to the New York Post online, the parents made this choice following some entirely personal considerations and without any scientific evidence. (*Il Giornale*, 11 September 2019)

The irony is tangible in this last excerpt as well in the shift from a neutral to a sarcastic tone and contributes to discrediting the issues espoused by RKC. Does this count as a form of rejection of refused knowledge?

¹⁷ “Barbara D’Urso ready for The Celebrity Island” published in *Messaggero*, 4 April 2014.

Thus far the answer has not been a straightforward one but requires some further elaboration.

9.6 Conclusions

This contribution is an attempt to complement other contributions on RKC in this book with an overview on the backdrop to many analyses of the ways refused knowledge can reinforce, circulate, and contribute to the shaping of specific social worlds. The analysis began with a research question derived from the evidence reported widely in the science communication literature regarding medialisation. Indeed, there is broad scholarly consensus that the media play a supporting role in science. Specifically, it has contributed to promoting the so-called social contract for science (Guston, 2000) and support its institutionalisation in society. In this way the media promote science's political legitimacy in a symbiotic relationship which falls into the medialisation category (Weingart, 2022; Rödder, 2011). Accordingly, it is useful to ask if there is a pattern consistent with such symbiotic relationship for the RKCs and, if so, how it is configured. One hypothesis is that the media actively refuse, by not covering, or discrediting, RKCs. Actually, the analysis provided in this chapter shows a more nuanced media's role or, at least, a less homogeneous one than might be expected. Rather than covering the various cases in the same way, the media coverage varied in accordance with the RKC issue dealt with. Analysis of TIPS project data revealed different levels of refusal, with analysis of coverage considering agenda-cutting, framing, and narrative hypotheses with a view to assessing the extent of publicly expressed discrediting of RKCs. Agenda-cutting (Buchmeier, 2020), here defined as withholding coverage or discrediting—as the 'Stamina Protocol' and 'Di Bella method' cases previously demonstrated—is consistent with the literature on the medialisation of science and the synergy between public science narratives and its political legitimisation. By building a science-non-science barrier, discursive exclusion (agenda-cutting) and public discrediting would also be expected to be relevant mechanisms given the frequency with which these are cited by RKC members and in their online media outlets.

Longitudinal analysis from 2010 to 2022 enabled us to detect different phases—one before the pandemic and another directly connected with the turbulent pandemic period, and the Italian mass vaccination campaign in particular. In addition to the pandemic, other turning points emerged, such as compulsory child vaccination by decree in 2017. These turning points worked differently in the Italian media context, as Sect. 9.4 showed, with the attention to (or refusal of) the issues raised by the four RKC's being unevenly distributed.

As Table 9.3 showed, in general it would seem that agenda-cutting was present in all the cases considered in this analysis but a number of differences can be detected. Although all four cases were affected by issue-omission, only pro-vaccine choice was covered sufficiently to be affected by issue-diminution and issue-removal. As the previous sections showed, in three out of the four cases, the discourse was mainly linked to news stories that were rarely covered: 5BLs, Stop-5G (or electro-sensitivity), and pro-vaccine choice were mainly covered when there was a local news or crime news connection. During the pandemic coverage also increased in line with the growing political engagement of the three communities. In this sense, for these three cases, agenda-cutting alone can be confirmed, with issue-omission certainly present during the pre-pandemic phase, while issue-diminution emerged during the pandemic. We cannot distil a specific indication from this evidence, except that anchoring was also applied to RKC's: the visibility of the pro-vaccine choice community definitely increased during the pandemic.

Qualitative analysis provided additional elements about the way RKC's are publicly presented.¹⁸ Framings of deviance for 5BLs and blame for pro-vaccine choice are coherent with a public discrediting strategy designed to protect the medical community in the former and public policy in the latter. For 5BLs in particular, this is coherent with the earlier well-known 'Stamina Protocol' and 'Di Bella method' cases. Indeed, during the pandemic period, many scientists referred to these cases as examples of malpractice, accusing politicians and journalists of being overly

¹⁸ It should be noted that the communities very rarely speak to the media themselves. Although this feature has not been properly thematised, it is significant that interviews on media outlet with pro-vaccine choice or 5LB are particularly rare and totally dominated by the accounts of institutional experts and scientists.

Table 9.3 Analytical scheme for the agenda-cutting, framing, and level of controversy processes

RKC	Coverage	Issue-omission	Issue-diminution	Issue-removal	Framing	Controversiality
Pro-vaccine choice	High	Yes	Yes	Yes	Blaming	High
5BLs	Low	Yes	No	No	Deviance	High
Stop-5G	Low	Yes	No	Yes	Politicisation/debunking and irony	High
Alkaline water	Very low	Yes	No	No	Consumerism/debunking and irony	Low

Source: Author's own elaboration of TIPS project's data

emotive or irrational. One final element relates to the underhand irony employed in relation to RKC issues that had already been debunked in public, further discrediting them publicly, as in the case of 5G and electro-sensitivity as well as alkaline water.

In line with the wide variety of coverage of the four issues considered, a single take-home message is difficult to discern, but two conclusions can be drawn: the media refuses refused knowledge under certain circumstances and via different strategies, i.e. not talking and discrediting when it did talk. Not talking about refused knowledge was not the principal strategy, but it was a significant one, as in the case of pro-vaccine choice, whilst talking about them may have been functional to supporting political health decisions based on scientific advice. In this case refusal is more underhand, using coverage in a blaming narrative. This reinforces the frame with irony to supplement discrediting and blaming.

Given the symbiotic relationship between media and science and technology, this analysis concentrated on naturally produced written texts, such as newspaper articles, on the assumption that these are proxies of media outlet orientations. However, the literature shows that these choices should be considered part of a more complex media ecology of the relationships between different actors. Agendas can be influenced by external and internal factors: the former includes advertisers, political pressures, and the role of public relations practitioners (Colistra, 2012) while the latter encompasses anticipatory obedience (Buchmeier, 2020) understood as compliance with normative ideas coming from other actors such as political institutions. Another potentially useful area of enquiry within this broad field is the resources that some RKC may lack. As medialisation scholarship has shown (Peters et al., 2008; Schäfer, 2011; Weingart, 2022) scientific institutions can marshal respected communication and press offices, while RKC generally do not invest in such communicative apparatuses but rather concentrate on channels such as social media. This is further proof of social world separation based on media representation. I have reported on representations of ‘corrupted science’ and rejected knowledge denounced as ‘irrational’. These representations can be retrieved from other sources (e.g. social media) and also traced directly through interviews with members of RKC. Perhaps the most important contribution of the present analysis is to show that media

provide a discursive resource for both social worlds. Media representations can fuel mutual accusations and discrediting. On one hand, it is a resource, a complementary part of the science narrative and part of a discourse designed to reinforce scientific institutions' value and role as potential political support for decision-making, especially at times of crisis such as the COVID-19 pandemic. In turn, the RKC narrative is configured as a symbolic resource for RKC themselves: blaming, mocking (irony), or openly accusing is a discursive resource supporting an antagonism and mistrust narrative. This fact helps us to describe a feature of the construction of the RKC social world: discourses as building blocks in a reciprocal relationship in which one side can hardly avoid talking about its counterpart. Once again, opposed social worlds are reproduced in a complementary way, as has emerged in the most recent research, including other contributions to this book.

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10

Respecifying Fieldwork: Refused Knowledge Communities Explored Through the Reflexive Lens

Barbara Morsello 

10.1 Introduction

Conducting qualitative fieldwork on refused knowledge-based social worlds, as well as building relationships with members of refused knowledge communities (RKC)s for research purposes, can be a challenging task for scholars exploring current ways in which the epistemic authority of science is being contested. Indeed, as has been highlighted by scholars engaged in the social studies of conspiracy cultures (Harambam, 2020a; Lepselter, 2016), followers of refused knowledge are not necessarily well disposed, or willing, to establish a dialogic relationship with academic researchers.

Indeed, refused knowledge followers share a widely held belief that academics in general act as spokespersons for epistemic regimes that they see as responsible for rejecting competing knowledge and claims at the margins of science, beyond the legitimate public debate. An additional

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element at stake in conducting fieldwork on RKC is related to the fact that their members may hold beliefs, values, assumptions and political positions in sharp contrast to those of researchers themselves (Kelley et al., 2020). Against this backdrop, in adopting a reflexive stance, this chapter explores the challenges that researchers engaged in studying the four RKC considered in this volume (see the Introduction of this volume) faced in their attempts to negotiate and conduct interviews with refused knowledge followers.

In so doing, I will argue that reflecting on how researchers handled the RKC interaction can provide relevant insights regarding the motivations and concerns driving people to dispute and distrust epistemic institutions. I thus highlight that *in itinere* reflexivity during fieldwork as well as an ex-post and distributed reflexivity may be crucial strategies.

Therefore, this chapter is based on a reflexive analysis of the various empirical materials I collected as a researcher conducting fieldwork on refused knowledge-based social worlds: (1) field notes (such as audio, visual and/or written materials) detailing interactions with members of the pro-vaccine choice community—the RKC I was most interested in; and (2) in-depth interviews with members of my research team regarding critical issues they faced in planning and conducting interviews with the four RKC with which we interacted during our research.

Field notes, as well as interviews with members of my research team, supported me in recollecting my fieldwork experiences and inspired my ex-post reflections on the action taken. All the materials were scrutinised with reflexive sensitivity. This deepened my understanding of how those who embrace refused knowledge relate to individuals rejecting the knowledge they believe in and was made possible by focusing mainly on how the researchers conducting the fieldwork were viewed by the RKC. Generally speaking, RKC see academic researchers as part of an epistemic regime depicted in the public sphere as bearer of ‘an epistemic supremacy’ towards other forms of knowledge (Grodzicka & Harambam, 2021).

During the fieldwork, RKC showed an ambivalent attitude to the assumption according to which society bestows ‘epistemic superiority’ upon academics and, in general, members of other scientific communities. On one hand, they attempted to exploit the interview interaction to

dispute the alleged epistemic authority of the researcher. On the other, research participants occasionally attempted to instrumentally turn such authority to their advantage with a view to disseminating refused knowledge claims and legitimising them beyond their specific social world of reference, thereby framing academic researchers as certifiers of ‘epistemic reliability’.

Despite refused knowledge followers’ ambivalent relationship with the academic researchers, my colleagues in the research team conducting this fieldwork and I were able to establish a trusting relationship with some members of the RKC by adopting the symmetry principle (Bloor, 1976; Wyatt, 2008; Lynch, 2020) and, by embracing epistemic agnosticism (see Chap. 2 by Federico Neresini), we fostered greater engagement in the research.

The remainder of this chapter is organised as follows. Section 10.1 provides an account of how reflexivity was entrenched in my fieldwork, particularly in the preliminary phases involved in building a trusting relationship with pro-vaccine choice for interview purposes. By analysing how the research team was viewed by respondents, Sect. 10.2 examines the way RKC alternatively represented researchers as ‘impostors’ (see paragraph 2.1) to be avoided or, by contrast, as ‘epistemic certifiers’ to be marshalled to improve the RKC’s reputation (see paragraph 2.2). This shows us the various legitimisation strategies in action, specifically boundary work and mimicry, which were explored in detail in the other chapters (see Chap. 2 by Federico Neresini and Chap. 7 by Stefano Crabu).

10.2 Negotiating Relationships with RKC as a Matter of Reflexivity

Gaining access to fieldwork is often problematic in qualitative research. In addition, researchers face challenging social interactions in negotiating relationships with research participants. Access to fieldwork is not, in fact, linear but rather a fluid, multifaceted and temporary process, simultaneously requiring researchers to be sensitive to what is going on in the field (Cunliffe, 2011), which implies acknowledging the implications of

negotiating access and building relationships with research participants (Cunliffe & Alcadipani, 2016). Negotiating access to the research field involves much more than entering an organisation, a community or a group and persuading participants to provide data. Generally speaking, negotiation begins with making calls, sending emails and writing letters to community gatekeepers (Fobosi, 2019) and does not end once fieldwork has been accessed or when approval for interviews has been obtained. Building relationships with participants is an ongoing process requiring careful management by researchers (Cunliffe & Karunanayake, 2013).

This implies that practicing reflexivity, as an ordinary, unremarkable and unavoidable feature of action (Lynch, 2000), can help researchers take stock of their own biases, experiences and assumptions and the social and cultural contexts in which the interaction with research participants occurs (Watt, 2007; Denzin & Lincoln, 1994; Maynard, 2003; Hammersley, 2019; Kenney, 2015; Cardano, 2014). This is a significant aspect to qualitative research because it also leads to a more accurate and valid interpretation of the data (Gouldner, 1968, 1971; Eriksson et al., 2012; Etherington, 2006). From this perspective, a few salient aspects need to be reflexively retraced.

First, taking charge of studying the pro-vaccine choice RKC involved a great effort on my part to negotiate an interaction space with them, maintaining high-quality access and improving our relationship by enhancing their trust in me and thus participation in the research. This was particularly important with other RKC's as well because, as we will see in Sect. 10.2, such communities are not generally willing to be interviewed and often have conflictual attitudes to researchers. During the initial steps of fieldwork negotiation, I realised that the issue at stake was not merely a matter of recruiting individuals for interviews, but of negotiating a trusting relationship with them and addressing their initial concerns. The perpetual risk of being rejected, in fact, emphasises the importance of re-strategising (Peticca-Harris et al., 2016) because achieving the trust of research participants is never absolute or given, but continuously negotiated.

All this meant that one of my ongoing strategies was spending time with research participants and joining their initiatives, from public demonstrations to local online groups and chats on WhatsApp or Telegram. I

also invited a few of them to go out for a drink or for a walk in a public garden before the interviews. I met pro-vaccine choice physicians and nurses in hospitals and carefully listened to their reservations regarding the COVID-19 pandemic and vaccination. Keeping in touch with followers of the RKC's studied was certainly a preliminary condition for successful fieldwork. However, spending time with them, being responsive to their questions, engaging in discussions, being welcomed into their homes before interviews where we shared lunches, dinners and conversations constantly evoked certain emotions, reactions and experiences that generally foster, rather than hinder, understanding of the world studied (Davies & Spencer, 2010; Behar, 1996). After a few encounters, I realised that these subjective experiences involved in negotiating research relationships with RKC's were not merely 'wasted time' before interviews but primary source of data to be translated, through careful reflection, into precious insights (Ploder & Hamann, 2020; Müller, 2016). Thus, being reflexive about this ongoing process of negotiation became an integral part of my understanding of them, providing insights into what leads people to engage in challenging epistemic institutions and distrust the knowledge generated by them.

Being welcomed into respondents' homes also helped me to grasp what adhering to, and supporting, refused knowledge in everyday life means. For example, meeting a mother who resigned from her job to home school her children, having lunch with a family which refuses technology in the form of a modern kitchen, TV or even a fridge in order to cultivate a more respectful attitude to life on our planet and so on were significant opportunities for trust-building as well as for consideration of the practical implications of embracing refused knowledge in everyday life from an insider perspective. This enhanced my understanding of the extent to which refused knowledge regarding health care or well-being is deeply rooted in a specific world view with profound repercussions on people's everyday lives and requiring great effort. In fact, RKC members frequently showed me their diets and supplements, the scientific papers they had found and the books they read as well as certain self-produced materials (Fig. 10.1) related to their life choices and support for their claims. This challenged me to read the documents and other materials they gave me, watch documentaries regarding the alleged (but not

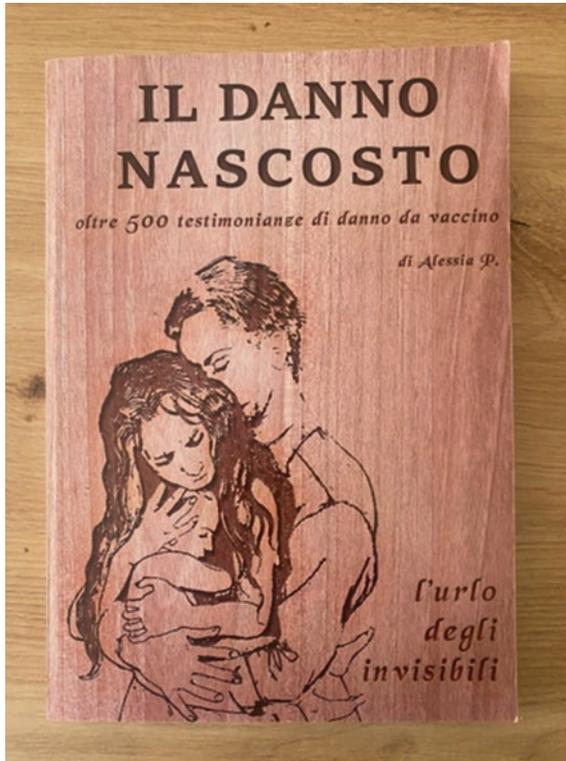


Fig. 10.1 Self-produced book by the pro-vaccine choice community entitled *The Hidden Damage*. (Picture taken by the author)

scientifically demonstrated) link between vaccinations and autism and return to them to discuss what I saw or read.

Before meeting pro-vaccine choice followers, it was important to acquire ‘native competence’ (Collins, 1998; Laudel & Gläser, 2007), without which I would not have been able to understand their claims, opinions and frames of reference. Indeed, respondents were frequently disappointed when I did not know what they were talking about or, by contrast, were pleased and amazed when I showed that I knew their references or the experts they considered reliable. Being aware of their opinions and claims, as well as their sources of information, was not only a means with which to gain their acceptance but also a way of being seen

by them as someone who wanted to know more about them beyond the stereotypes recurrent in the public sphere which discursively frame pro-vaccine choice followers as ignorant, misinformed and irrational.

This also gave me a chance to get closer to their point of view on reality. Consequently, for example, one research participant gave me a ‘gift’: a book with over 500 personal stories of supposed vaccine damage collected by a local pro-vaccine choice community and paid for via crowdfunding (Fig. 10.1). On numerous other occasions pro-vaccine choice followers provided me with their sources or suggested reading to increase my knowledge of their reasons for refusing vaccinations. During the fieldwork, some of them also sent me links to blogs, news or videos they considered important on WhatsApp or invited me to join group chats on Telegram in which they shared news, events and discussions. This gave me an insight into the substantial amount of time they spend selecting their informative sources by reading books and articles and collecting information they considered relevant in support of their cause.

To support my reflexive approach, at such times I collected field notes to document my experiences with the pro-vaccine choice followers and record comments and discussions when we were not audio-recorded (Eriksson et al., 2012). My field notes were essential and enabled me to record episodes of rejection and hostility to my invitations to take part in the research.

Furthermore, my field notes also gave me the chance to reflect on how the research context—by which I mean specific sociocultural events or conditions with the potential to affect the phenomenon studied—shaped my encounters with research participants and the interview setting, as has been noted by many others, such as Phillippi and Lauderdale (2018) and Mauthner and Doucet (2003). Moreover, studies on conspiracy cultures have shown that the research context in which participants, and researchers, are embedded is key to achieving a more in-depth understanding of communities centred on alternative or refused knowledge and belief systems (Harambam, 2020a).

In my case, during my fieldwork with pro-vaccine choice supporters, the COVID-19 pandemic was an event that played a leading role in reconfiguring my strategies for interacting with research participants, as well as those of my colleagues, requiring changes to research participant

recruitment, reconsideration of the form and venue of interviews and a consideration of the changes implied by the different settings. In fact, online calls were made in certain cases in accordance with social distancing measures, even if this sacrificed the familiarity that in-person interviews give or, by contrast, opting for in-person interviews whilst being aware that it was potentially dangerous.

The presence of this global outbreak in the background of our research was an unfortunate circumstance in many respects, despite offering a unique opportunity to understand the RKC's viewpoint. Indeed, the strict virus containment restrictions adopted in Italy forced the RKCs out into the open with their different approach to life and health (see Crabu, in this book), requiring them to adopt a public stance on mandatory vaccinations and/or anti-COVID norms such as mask-wearing and testing when these became prerequisites to entering social spaces and taking part in public life. Simultaneously, this situation heightened our risk of rejection by the RKCs, with suspicion by them occasionally prompting them to withdraw their availability for interviews, as I will examine in greater depth in Sect. 10.2. It is well-known, in fact, that pandemics exacerbate social relationships between people who support public policy and those who oppose them (Cohen, 1973; Lasco, 2020; Lasco & Curato, 2019). Over the two years of the COVID-19 pandemic, it was easy to find public demonstrations and people expressing their disagreement with anti-COVID measures or vaccinations (Fig. 10.3) by leaving messages all over various cities, as Fig. 10.2 shows. Public spaces became RKC conflict arenas (see Morsello, Neresini and Agodi in this book) and required greater effort by researchers to build a trusting relationship with research participants, as the next section makes clear.

In my case, the complexities involved in building lasting relationships of trust with pro-vaccine choice supporters for research purposes and the conflict characterising the general social context in which my research was conducted prompted me to reflexively share such experiences with my colleagues. During the weekly/monthly meetings with my research team, my colleagues and I often shared our field experiences and these became powerful insights with which to reframe our understanding of our subjective experiences with RKCs and the peculiarities of each community. Moreover, the wealth of experiences reported within these group



Fig. 10.2 'Breathe. Their cure is worse than the disease'. (Trento, 12/12/2020, picture taken by the author)

discussions convinced me to implement a distributed reflexive activity process (Cunliffe, 2020; Gherardi et al., 2018; Lynch, 2017) in the research group once the data collection process had ended. I did so by inviting the researchers to personal interviews with me and they all accepted my invitation. My three in-depth interviews with members of the research teams directly in charge of the fieldwork with Stop 5G, Alkaline Water and 5BL communities were designed to collect in-depth accounts of the main problems encountered in building a relationship with RKC's followers.

What I did, in fact, was to ask my colleagues to report episodes that were significant for them, focusing on their relationships with the RKC's, thereby highlighting the difficulties bound up with recruitment but also fostering reflection on the strategies used to cope with the main problems associated with working with RKC's during the COVID-19 pandemic.



Fig. 10.3 'No compulsory vaccination'. Public demonstration against anti-COVID vaccination. (Trento, 5/07/2021, picture taken by the author)

10.3 The Complicated Relationship Between RKC's and Academic Researchers

In reflecting on how the relationship the research team and I developed with RKC's members evolved, two main aspects required particular attention. I focused on how researchers were experienced by interviewees, who alternatively attempted both to question researchers' epistemic authority and to take advantage of it to gain visibility and improve their own reputations. In this sense, researchers were alternatively framed as 'impostors' (see Sect. 10.3.1) and 'epistemic certifiers' (see Sect. 10.3.2).

10.3.1 'You are a Charlatan!': Academic Researchers as Imposters

As I mentioned earlier, the project's researchers were experienced as impostors by RKC members. Woolgar et al. (2021) defines impostors as engines of indeterminacy, uncertainty and disorder and observing the frictions and disruptions related to them can provide significant insights into the constitutive dynamics of the social relations and cultural settings of the communities observed.

'Imposters' are a topic of interest in social science and humanities and Woolgar et al. (2021) simply define them as individuals who pretend to be someone else to deceive others, thereby disrupting the social order. Suspicions of this sort have a profound impact on people's lives and social interactions within groups primarily because 'imposters mean trouble and stir a wide range of societal responses ranging from intrigue to suspicion, from outrage to horror' (Woolgar et al., 2021, p. 3). For these reasons, in our case, not only did being framed as impostors enormously complicate relationship building with RKC members but it also shed light on the dynamic by which RKC members assess the institutions researchers belong to.

In my case, in fact, each individual interview with pro-vaccine choice supporters resulted in a major, time consuming and occasionally exhausting negotiation during which I was given 'the third degree' and doors were often shut in my face for a variety of reasons: 'we don't want to give more tools to the institutions to figure out how to convince us to vaccinate', 'we have already trusted you (academics) once and our words were misunderstood!', to cite just a few examples. During one interview I was accused of being 'the perfect pawn in the system' by a doctor who did not want to be audio-recorded. What he meant was that even though I presented myself as a university researcher, in his opinion I was part of a wider power system designed to collect information on citizens out of step with prevailing opinions—for example, on anti-vaccination norms. His accusation was based on the fact that as a young woman belonging to what he conceived of as the 'academic elite' I came across as trustworthy increasing the likelihood that ordinary people would be taken in by me,

as he saw it. Being framed as part of the ‘academic elites’ also often implied being considered an impostor attempting to obtain information on RKC, potentially leading to refusal to take part in interviews or rejecting all contact with researchers, as one of my colleagues who dealt with the Stop 5G community reports:

Because anyway, I have to say that everyone was very distrustful of me precisely because they identified us as the ‘academic elite’ and for this reason it was difficult to gain their trust in some cases. (...) I realised that there was very strong resistance, hostility toward academia or, more generally, toward knowledge not considered ‘valid’ by them. The first contacts I made for the interview (...) were always rejected outright or totally ignored. (Transcript of researcher interview, 10/06/2022)

From the RKC’s perspective, the ‘academic elites’ were conceived of as having a supreme epistemic authority in science-related decisions and orienting policy as in the case of the COVID-19 pandemic. In certain cases, it seems reasonable that academia can be considered a rather powerful, elite institution (Kelley & Weaver, 2020) and regarded as having epistemic authority in the public sphere. However, for a few respondents, this superiority led to charges of financial gain by this purported ‘academic elite’, much to the detriment of citizens. In fact, the universities and academics in general are often seen by RKC as part of a belief system created to further the economic and political interests of private biotech corporations (Mede & Schäfer, 2020).

Other reasons underlie RKC lack of trust in academics and their labelling of them as impostors. In certain cases, they believe that academics address their concerns and claims in a manner considered ‘unfair’ or ‘inaccurate’ and are consequently sometimes extremely reluctant to engage in trusting relationships with them (Emerson & Pollner, 2001). Another problem, as Chess and Shaw (2015) have argued, is that many academic discourse conventions and everyday practices can come across as mysterious and threatening to lay people and anxieties regarding what academics may be doing with their words was found to be widespread among numerous potential interviewees.

On other occasions, for example, even if I was not framed as part of the academic elite, as a researcher I was perceived as representing the Ministry of University and Research by which some RKC followers felt ignored, contested and occasionally mocked for their trust in refused knowledge.

From their perspectives, then, researchers are impostors because they contribute to supporting a power system in which institutional science serves the power and interests of the few. In many cases, this led to what researchers perceived as great hostility to them in their attempts to interview RKC members.

In my case, this was clear when I asked them to read and sign the informed consent form (Fig. 10.4).

While the interview consent form (Fig. 10.4) is a preliminary and mandatory step in interviews in order to guarantee participant data anonymity, it was often viewed with suspicion by interviewees, with several refusing to sign it. One of the reasons for this was related to the symbolic

Scelte alternative per la gestione della propria salute

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Descrizione del progetto

Il progetto (finanziato dal Ministero dell'Istruzione, dell'Università e della Ricerca) analizza in che modo cittadini e comunità della società italiana fanno ricorso a conoscenze alternative per affrontare problemi e prendere decisioni in merito alla loro vita, come per esempio l'uso della medicina alternativa per far fronte alla malattia. Nell'ambito di questo progetto, le conoscenze alternative comprendono quei saperi che non trovano spazio all'interno della comunità scientifica, o faticano ad essere riconosciuti come legittimi dagli esperti.

Obiettivi del progetto

Il progetto di ricerca studia l'insieme delle condizioni sociali, culturali e biografiche che orientano le persone a utilizzare conoscenze alternative alla scienza, con particolare attenzione a quelle alternative o in conflitto con la medicina convenzionale. I principali obiettivi sono:

- identificare in che modo le conoscenze alternative alla scienza vengono comunicate e condivise, sia nei media tradizionali (televisione e carta stampata), sia in quelli basati su internet (social networks, blogs, e pagine web);
- comprendere le motivazioni che guidano le persone nel riportare fiducia nelle conoscenze alternative alla scienza, specialmente quelle che hanno a che fare con la cura del corpo e il benessere della persona;
- studiare i rapporti fra la scienza e le conoscenze alternative.

Strategia

Il progetto di ricerca, attraverso focus group e interviste, coinvolge persone e comunità della società civile che, nel corso della loro vita, fanno o hanno fatto affidamento alle conoscenze alternative alla scienza. Oltre a produrre un'analisi più accurata del come questi saperi emergono, vengono legittimati e considerati affidabili, il progetto promuoverà una riflessione più ampia sulle implicazioni etiche, sociali, politiche ed economiche derivanti dalla diffusione di forme di conoscenza alternativa.

Consenso, per l'intervistatore, all'intervista e all'uso delle informazioni date

Titolo del progetto di ricerca: Scelte alternative per la gestione della propria salute

Istituzione di ricerca: Università di Padova (PD)

Nome dell'intervistatore e del curatore della raccolta: Barbara Morvello

Sono stato informato circa il progetto di ricerca e il modo in cui il mio contributo potrà essere usato. Mi è stato spiegato come la trascrizione dell'intervista, e/o l'ascolto della registrazione audio/video relativa, sarà assicurata riservata, salvo il mio assenso a renderla pubblica.

Il mio contributo sarà conservato in luogo sicuro, e ne sarà consentito l'accesso solo a coloro che ne ricevono il permesso dall'intervistatore.

Sono a conoscenza che posso ritirare il mio assenso in qualunque momento informando l'intervistatore, per cui accosento all'intervista che sto per concedere all'interno del progetto di cui sopra, intervista che potrà essere usata solo per i fini della ricerca (incluse pubblicazioni e rapporti di ricerca), e in forma strettamente anonima, dall'intervistatore*.

Firma _____ Data _____
(dell'intervistato)

Firma _____ Data _____
(dell'intervistatore-curatore)

* La riservatezza dei dati personali è comunque tutelata dal "Regolamento Generale sulla Protezione dei Dati" varato dall'Unione Europea (GDPR - 2016/679), e in ottemperanza della legislazione italiana (D.Lgs. 101/2018).

Fig. 10.4 Interview consent form

dimension of the form: the logos of the universities involved in the study, the reference to the EU's GDPR 2016/679 regarding privacy, which were considered in a few cases as 'proof' that we were imposters attempting to deceive them, because most of our interviewees no longer acknowledge delegation to the EU to protect their privacy and sensitive data. In certain cases, the phrasing of the form was framed as evidence supporting my supposed impostor role in their eyes:

A few days after the interview both S. and her husband stopped answering my phone calls.

I remained on hold. After several attempts to contact S., she finally answered. Unfortunately, she had decided that I was no longer worthy of her trust. I was hurt and frustrated. I had worked so hard for them to trust me: we had had lunch together, I had played with their daughter, they had told me about their life together and the work difficulties they were going through. They offered me apple pie and invited me to the park. S. lent me an important book: a collection of witnesses from families claiming vaccine harm. I was supposed to give it back to her when I returned to interview her husband. What went wrong? S. said that after reading the interview consent form again, they got worried. The label 'alternative knowledge' had not convinced her. (...) It is an ongoing negotiation, and I don't know what to do anymore. (Transcript of author field note, 08/04/2021)

Despite our efforts to use inclusive language mindful of the cultural and social specificities of the communities studied certain words were perceived as signs of 'impostering'—for example, as reported in the above field note, the label 'alternative knowledge' was regarded with suspicion by the interviewee, who went as far as withdrawing her consent. During discussion of this at our research team meeting we concluded that the respondents did not conceive their knowledge in terms of 'otherness', or as an 'alternative' to official knowledge, but rather as knowledge that was legitimate, *per se* but rejected or denied by the establishment, such as universities and other epistemic institutions.

This was tangible in the use of the 'no vax' label. Although other research (Francia et al., 2019) has found that 'no vax' or 'anti-vax' are the most common labels in the scientific literature to refer to communities fighting compulsory vaccination, during our interviews I noted that the

term preferred by these communities is pro-vaccine choice which they see as better emphasising the fact that they are not 'against' vaccination *per se*, but 'for' freedom of choice.

Hence, using what they consider as the wrong expressions, such as mainstream media terms (e.g. 'no vax' is frequently used in newspapers; also see Chap. 9 by Paolo Giardullo) can be framed as the language of the enemy and researchers using it are thus likely to be seen as impostors.

Moreover, the symbolic meaning that certain objects acquired as a consequence of the COVID-19 emergency played a central role in framing researchers as impostors or, at least, not worthy of trust. Face masks and vaccinations were potentially controversial objects for RKC members and crucial in defining the research setting. Thus, when these were physically present during interviews, they were often used to 'test' researchers' reliability and I soon realised that removing my face mask or not being vaccinated were 'keys' to accessing their trust. For pro-vaccine choice supporters, in fact, wearing a face mask during an interview was not perceived as a good sign: whilst some respected researchers' freedom of choice in wearing a face mask, it was still conceived as a kind of acquiescence to the 'power' of the state, a symbol of fear, rather than an individual protective device against contagion. On the other hand, removing a face mask during an interview was considered a demonstration of 'free thinking' and not being vaccinated also implied being 'one of them'.

As we have seen, the COVID-19 pandemic had a profound impact on my research action and, in few cases, I opted for online interviews on Zoom or Skype. However pro-vaccine choice supporters preferred to be interviewed in person on a great many occasions. For them an in-person meeting was not a vehicle of infection but rather the only way for them to trust researchers and reduce the risk of them being impostors: the pandemic objects thus defined the limits and potential of interaction within the interview setting. The result of this for me was constant tension between my research-related requirements and my desire to protect myself from infection. The risk of being perceived as an 'impostor' by RKC members required constant interview renegotiation. Nevertheless, I chose to conduct interviews in-person, attempting to follow social distancing rules and avoid contact with my loved ones for the rest of the week during the most difficult phases in the COVID-19 pandemic.

This negotiation process also concerned my personal values and beliefs, for example, when I introduced myself, I was often asked: ‘whose side are you on?’. This highlighted that a ‘neutral posture’ does not exist (Scott et al., 1990), even when assuming a symmetrical perspective (see Chap. 2 by Federico Neresini). To avoid the risk of being framed as an impostor, I often answered this question by explaining that my aim was to understand their views without questioning the veracity or accuracy of their claims. I always told them that my interest was understanding RKC viewpoints even if I was fully vaccinated or did not agree with them regarding the pandemic. This response did not always satisfy interviewees. In the worst case scenario it was considered a lie, since I was assumed to be hiding my opinions from them whilst on other occasions it was key to establishing a relationship of trust and avoiding being framed as an impostor.

I adopted many strategies to increase my chances of being granted interviews rather than being framed as an impostor. One of these strategies consisted of being introduced to pro-vaccine choice supporters by people who were not part of what they considered the ‘establishment’. These ‘ordinary people’—not what they regarded as corrupt academic elites (Mede & Schäfer, 2020)—were trusted work colleagues, forest-kindergarten teachers, paediatricians in favour of freedom of choice in vaccination, members of RKCs and participants in public demonstrations. Involving people with whom interviewees had established a relationship of trust as gatekeepers served to increase the likelihood of a positive reception by RKC members.

However, even if enrolling gatekeepers to acquire more information or to be accepted by research participants is very common in qualitative research, this is often omitted with the aim of providing a more linear and ‘acceptable’ version of research design (Fine, 1993). On the other hand, in order to recruit 5BLs or Alkaline Water exponents, my colleagues chose to participate in their online and offline training events and feedback was thus a long time in coming. Moreover, researchers working with Stop 5G communities took part in public demonstrations, a strategy that elicited quite a few misunderstandings, as I will report in the next section.

As regards pro-vaccine choice community members, as I discussed in Sect. 10.1, spending time with these was of use in overcoming the risk of

being considered an impostor. Having dinner, a drink or breakfast together, going for a walk or suggesting lunch was a way of gaining confidence and overcoming fears.

10.3.2 Are You Recruiting Them or Are They Recruiting You? Exploiting Researchers

Rather than being suspicious or hesitant regarding researchers' affiliations, some RKC followers attempted to make use of them. In certain cases, I observed that researchers were framed as epistemic resources belonging to established public institutions whose research authority interviewees attempted to make use of to increase acceptance of refused knowledge in the public sphere.

In such cases researchers were made use of by RKCs as 'epistemic certifiers', i.e. individuals or groups with specialised skills and knowledge used to assess the credibility or reliability of scientific knowledge claims (Collins, 2004). In fact, epistemic certifiers play a crucial role in the scientific enterprise, as they are responsible for determining which claims and evidence can be considered trustworthy. Academic researchers play an important role in the production and dissemination of expert knowledge and can be considered epistemic certifiers in the sense that they are also recognised as experts in their fields (Martin, 1991). Thus, through their expertise, researchers contribute to establishing and maintaining the standards of credibility and reliability that are necessary for scientific knowledge to be accepted and trusted (Latour, 1987; Latour & Woolgar, 1986; Law, 2004). This is also true for RKCs when they attempt to exploit researchers' ability to foster the acknowledgement of refused knowledge claims in the public sphere.

I will now reflexively reconstruct the various ways by which certain RKC members attempted to make use of researchers as epistemic certifiers. Considering pro-vaccine choice RKCs, for example, I noted occasional attempts to access researchers' networks—i.e. gain access to a possible audience by leveraging a researcher's reputation. An example is what happened to me with a pro-vaccine choice doctor who was initially willing to be interviewed but then asked me to promote the contents of

the interview within my academic network and share the contents of the interview with colleagues to find sympathisers, as I reported in my memos:

Following a telephone contact with G., a doctor, he asked if I could promote the content of the interview through my network of academic contacts. I was surprised. This aspect is very interesting for me as it denotes the need for credibility even within academic networks. Looking for credibility among academics can be interpreted as a desire to position themselves within spheres with the potential to increase follower numbers with the interview being used as an entry-point and my academic degree and affiliation as a form of legitimacy. I had to explain to him that the interview would remain anonymous and would not be releasable. He seemed a bit disappointed with this. (Transcript of my field notes, 07/03/2021)

This is important for the RKC, as their knowledge claims compete with scientific knowledge, often through various mimesis strategies (see Chap. 2 by Federico Neresini). In this context, making use of researchers is central to legitimising claims in the public sphere. In addition, mobilising those perceived to be ‘independent scientific experts’ (e.g. not colluding with the scientific, political and economic establishment) is a common RKC strategy designed to increase the credibility of their claims (Crabu et al., 2022). In fact, they strive to exploit not only the researcher’s networks but also their credentials.

Indeed, attempting to take advantage of an interviewer’s credentials—such as academic qualifications and affiliations—is a specific strategy employed by certain RKC members to improve their authority and legitimacy within their communities. This is particularly true for the Alkaline Water RKC that mainly comprises sellers of devices serving to alkalize water and representatives of specific brands. For these, an interview is an opportunity to gain credibility amongst the alkaline water community’s members. There is nothing new about researchers being seen as epistemic certifiers or certain respondents attempting to exploit their network and/or their professional credentials, as similar credibility attribution methods have been used in various scientific or alleged scientific knowledge forums (Collins & Pinch, 1979; Collins, 1998). The difference lies in the things the above cases showed researchers were ‘asked’—providing

contacts or spreading messages among professional networks and this complicate the interaction with RKC.

In other cases, RKC engaged in efforts to ‘recruit’ researchers, during interviews and also afterwards:

Our problem during fieldwork was that they wanted to ‘recruit us’! They wanted to legitimise their knowledge through our research, and this ambiguity was difficult to manage. Because the first thing we do is try to be accepted by interviewees ... but actually they are so happy to give us information, they are very accommodating with researchers. We were very careful not to be recruited, but ambiguity regarding this was difficult to avoid. During interviews, they would then share the news on Facebook, for example. (...) They also used, or tried to use, our institutional scientific credentials to legitimise their knowledge. So, many times we risked becoming ‘tools’ for their ‘patchworks of knowledge’. And this was something we had to bear in mind not to avoid building relationships with them, but to avoid being recruited or used to support their refused knowledge. This was a crucial point. (Transcript of researcher interview, 22/06/2022)

The risk of being recruited as an epistemic certifier was difficult to avoid in certain situations, because building a relationship of trust with interviewees was important to the success of the interview (Kuehner, 2016) and we thus attempted to be always open to such requests. This was difficult to achieve on various occasions, however, because RKC often use social media pages such as Facebook to promote events, activities and news (Bory et al., 2021, 2023) and this also involved meeting with researchers. On a couple of occasions followers of Alkaline Water RKC members created online posts and shared these among their online communities, with interviews being presented as personal successes for respondents, as well as important achievements for the community, as the post below makes clear:

(Text from the post above—Fig. 10.5) One way or another, it’s back to university!!!

Giving my contribution to a Federico II University of Naples Research project on Ionized Alkaline Water in Lifestyles, Health, and Wellness was an honour. Over three years, we have helped hundreds and hundreds of

In un modo o in un altro si torna all'Università! 🗨️ 🙏 🙏
 Dare il mio contributo in una Ricerca dell'Università Federico II di Napoli in merito all'Acqua Alcalina Ionizzata negli stili di vita, Salute e Benessere è stato un onore.
 In 3 anni abbiamo aiutato centinaia e centinaia di famiglie... e nel 2021 abbiamo iniziato ancora meglio!! Abbiamo già cambiato l'abitudine di molti.
 Sempre grazie a Dio 🙏



👍❤️ 134

Commenti: 57 Condivisioni: 4

Fig. 10.5 A member of the Alkaline Water community, sharing a picture taken during a Zoom interview, FB page, 01/04/2021

families ... and 2021 has got off to an even better start!!! We have already changed the habits of many. Thank God always! (Quotation from a post on an Alkaline Water FB page, 01/04/2021)

The post was also accompanied by featured personal images (Fig. 10.5) in which users portray themselves as worthy of trust on the basis of interviews by academic researchers. Gaining public recognition for RKC's thus also involves recruiting epistemic certifiers belonging to established scientific institutions.

Other recruitment attempts, specifically reported by researchers dealing with No-5G RKC's, involve efforts to turn researchers into activists.

On certain occasions, interest in RKC claims shown by researchers was assumed to be somehow a tacit request to become part of their social world. As other studies have also reported (Harambam, 2020a), the risk in adopting an agnostic perspective is that researchers can be portrayed as lending support to such causes from mainstream media or academics. In our case, specifically with people fighting to block the installation of 5G antennas, researchers took part in public demonstrations to meet privileged witnesses for interviews and this created quite a few misunderstandings with respondents, as one researcher reports:

When they try to convince researchers of the validity of their scientific positioning, you get used to it and play along. But once I felt guilty. It happened when I saw an interviewee during a demonstration against 5G and another time also with a very nice lady who was involved in the Italian '68 movement. They talked to me about young people's lack of interest in health-related issues, and so saw my interest as a researcher in the 5G topic as notable. I had the feeling that it was an opportunity for them to recruit me, as a potential young 'Stop 5G' activist! I felt almost guilty about that because that was not my intention. I never said to them that I was interested in becoming an activist! I always said that I was a researcher exploring the Stop 5G issue, but I never said that I wanted to become an activist! But still, they interpreted my interest in the topic and our meetings as an opportunity to recruit me (as an activist). (Transcript of researcher interview, 14/06/2022)

As the researcher reported, meetings with members of the Stop-5G RKC were often turned into recruiting opportunities for the latter in which researchers were viewed as allies, as epistemic resources via which to strengthen the RKC. However, some of those interviewing experts on the 5BLs had other views:

The experts (members of 5BLs communities) probably wanted to exploit our interviews as a form of legitimisation of their positions or at least as an 'alternative amplifier' to overcome a series of situations in which they failed, for example, with the media. Indeed, they often claimed that the public debate and the media demolished them or were very critical of them. (Transcript of researcher interview, 12/07/2022)

As with the Alkaline Water RKC, 5BLs experts use interviews to spread their message and researchers as epistemic resources with which to legitimise their claims, often after unsuccessful earlier attempts to spread their message within the mainstream media. They frequently felt betrayed, and occasionally ridiculed, by journalists and public opinion, as we have seen. In the above case, 5BL followers also viewed interviews with researchers as opportunities to enhance and refresh their reputation in the public sphere.

10.4 Conclusion

As Fine (1993) noted, frequently in qualitative research the process of conducting fieldwork remains hidden in the backstage of social research. Analysis is private research group activity and thus field notes and other related materials collected and produced by researchers are rarely available. This makes the role of our biographies and social positions as researchers implicated in the act of exploring and understanding even more opaque (Geertz, 1968, 1973; Back, 2004). But what happens if we restore the epistemic value of data collection as a complex and non-linear process of negotiation with research participants? What is to be gained by reflexively analysing researchers' fieldwork experiences?

In my case, it would seem to increase our understanding of the concerns and motivations that drive people to dispute and distrust scientific institutions. As Latour and Woolgar (1986) showed in *Laboratory Life*, exploring and reporting the means by which observers are conceived, addressed and occasionally even labelled by research participants reveals important aspects of scientists' culture and epistemic assumptions. Similarly, observing how researchers were framed by RKC members was of use in understanding the implications and practices of refused knowledge legitimisation as well as casting light on the ambiguity of this process. For example, it is clear that, on one hand, researchers were sometimes viewed as 'impostors' and, thus interviews rejected whilst on the other hand, the opposite can also occur with researchers being framed as 'epistemic certifiers' and thus subjected to more or less overt attempts at exploitation or recruitment by RKC members.

Reflexively considering that researchers are framed as ‘impostors’ or ‘epistemic certifiers’ reveals the way that RKC’s often demonstrate a great appreciation of science which takes the form of idealised science that is not personified by us as institutional scientific spokespeople. By contrast, when RKC’s attempt to enrol us as ‘epistemic certifiers’ or activists it implies that they are often and sometimes reluctantly considering science and its institutions as a valid resource in their effort to legitimise their knowledge claims.

Thus, reflecting on how the researchers experienced the fieldwork was an important way of examining RKC’s ambivalent relationship with mainstream epistemic authority in greater depth. Moreover, reflecting on the relationship between researchers and participants also throws light on the way that some of the legitimisation processes pursued by RKC’s can be somewhat similar to those in action within the scientific research community. For example, the alignment of actors in order to reinforce the epistemic authority of claims and the use of epistemic certifiers to establish reliability also play a fundamental role in science.

Our reflexive exercise also highlighted that establishing a high-quality relationship with RKC’s was a matter of spending time with them, keeping up-to-date about their theories and the reasons underlying their claims, being aware of the contextual elements potentially affecting our relationship with them, such as COVID-19 policies, and thus, overcoming the binary ‘science’-‘conspiracy theory’ dichotomy (Safford et al., 2021). In challenging or exploiting epistemic authority, RKC’s are not simply interested in avoiding sanctions or the consequences of not adhering to certain social norms and public health policies nor in irrationally pursuing theories spawned from online misinformation, but rather in legitimising refused knowledge in the public sphere with the aim of gaining supremacy in certain epistemic battles—such as the ‘Corona Truth War’ (Harambam, 2020b), the vaccinations controversy and the installation of 5G antennas—and being acknowledged as having the legitimacy to contest them in light of the refused knowledge they produce, promote and support.

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11

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

Federico Neresini and Stefano Crabu

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 RKC’s 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 RKC’s. Hence, while contributing to the framing of RKC’s 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 RKC and ourselves.

11.1.1 Refused Knowledge Communities and Us

This book has highlighted that RKC 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 RKC 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 demagoguery, 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: RKC's operate within a constantly changing dynamic which shifts together with its historical, political and socio-technical contingencies. Such contingencies potentially rearrange relations between RKC's 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 RKC's (as irrational enemies) within the subjectivation and counter-subjectivation 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 RKC's 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 RKC 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 RKC 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 RKC 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 RKC 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 RKC 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 RKC themselves is therefore performative, in the sense that representations of RKC 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 RKC's 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 RKC's 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 RKC's, 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 RKC's 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 RKC. 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 RKC 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 RKC 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 RKC to express strong reservations or harsh criticisms of the merits of conspiracy theories. Therefore, using this concept to stigmatise RKC 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 RKC 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 post-normal 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 anti-scientific, 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 RKC 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 RKC 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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