



# 7

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

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### 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’)<sup>1</sup>

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

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<sup>1</sup> 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*)<sup>2</sup>

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)

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<sup>2</sup> 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 Institute<sup>3</sup> 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

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<sup>3</sup>The 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.<sup>4</sup>

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

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<sup>4</sup> 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)<sup>5</sup>

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

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<sup>5</sup>The 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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