T/S ESSAY

# Rediscussing the Primacy of Scientific Expertise: A Case Study on Vaccine Hesitant Parents in Trentino

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#### **Abstract**

Vaccine hesitancy constitutes a pressing social issue. Media and institutions frequently portray vaccine-hesitant parents as ignorant and anti-scientific. This exploratory study - conducted in the Autonomous Province of Trento (Italy) in 2018 - analyses organized parents opposing the reinforcement of childhood vaccination mandates. Semi-structured interviews with vaccine-hesitant parents and physicians with experience with vaccine-hesitant patients, and participant observation were conducted to understand the perceptions of childhood vaccination mandates, focusing on narratives regarding the role played by science and scientific experts in the vaccine debate. Analysed through the lens of sociology of health and Science and Technology Studies, results highlight that vaccine hesitancy cannot be reduced to anti-scientific attitudes. Hesitant parents' vaccination decisions are based on a different perspective of their children's health and on alternative forms of expertise; there are persistent weaknesses in the doctor-patient and expert-citizen relationship in a deeply dualistic vaccine-related debate; and there is the need for a dialogue between institutions and vaccine-hesitant parents.

#### Keywords

parental vaccine hesitancy; childhood mandatory vaccination; trust in science and scientific experts; alternative expertise; reflexive patients; science communication.

### 1. Introduction

In a context of increased global health threats (Daszak et al. 2020; The Lancet Planetary Health 2021), including the recent Covid-19 pandemic, and the development of new vaccines, the global relevance of the phenomenon of vaccine hesitancy has come to the fore. Vaccine hesitancy can be defined as "a delay in acceptance or refusal of vaccines despite availability of vaccination services" (MacDonald et al. 2015, 4163). It is a complex phenomenon, which is both country-specific and vaccine-specific, and can vary over time. Given its widespread occurrence, vaccine hesitancy was recognized by the World Health Organization as one of the "ten threats to global health in 2019".

Vaccines have been designed to prevent pathogen-specific infections (Pardi et al. 2018), reducing the hazards and risks of contracting vaccine-preventable diseases. Vaccines are technologies

that have both a global and a more personal, local characteristic. They are "produced, distributed and monitored within systems that are equally globalized" (Leach and Fairhead 2007, 2) to potentially reach a global population (with specific attention to children) and, at the same time, they reach into the private health sphere of individuals. As technoscientific innovations, vaccines have a "hybrid" character in the public debate, requiring the simultaneous management of "technical" uncertainties with those related to their social, economic, and political purposes and implications (Bucchi and Neresini 2006). Indeed, as the Covid-19 pandemic has shown, technological, scientific, economic, political, and cultural aspects of vaccines often appear to be inseparable, bringing together fears of ill health with those of excessive medicalization, adverse events following immunization (AEFI)<sup>2</sup>, and the increasing centralization of power and economic resources in the hands of few pharmaceutical companies. Indeed, uncertainty around vaccines is also due to their "hybrid" character in the public debate (Bucchi and Neresini 2006).

In recent years, several European countries have adopted revised vaccination strategies, introducing or increasing the number of mandatory vaccines for children, and embracing different approaches to (non-)compliance (Odone et al. 2021). Italy was the first European country to introduce an increased number of mandatory vaccines in line with its official role as a leader in vaccine strategies worldwide – in accordance with the Global Health Security Agenda of 2014 (Centers for Diseases Control and Prevention 2014). When addressing vaccination policies and strategies, as well as other public health issues, a delicate balance between individual rights and collective interests should be considered. The choice between a more "traditional" strategy focused on imposing a vaccination obligation contrasted with a strategy focused on the recommendation of vaccines, depends on how institutions have decided to manage vaccination dissent. In either case, both the communication strategies adopted, and the broader relationship established between institutions (be they health, political, or scientific) and citizens over time, play an important role.

The motivations that lead to parental vaccine hesitancy have often been misunderstood and misinterpreted by the media and political and health institutions – leading to a sharp polarization of the vaccine-related debate (Brunson and Sobo 2017; Vanderslott et al. 2022). Explaining vaccine hesitancy in terms of "the media, ignorance and misinformation, class or predisposition" can lead to misleading and ineffective policies (Poltorak et al. 2005, 718). It is similarly unproductive for political and health institutions to approach the phenomenon as caused by either a general distrust in science (and scientists) or a general scepticism towards vaccination (Bucchi et al. 2022; Peretti-Watel et al. 2015), and by accusing vaccine-hesitant parents of being anti-scientific (Gottlieb 2016; Ward et al. 2019). Framing vaccine hesitancy as a fight against science and scientific expertise does not help to increase trust in vaccines; it reduces "the controversy to the status of vaccine science" (Goldenberg 2021, 15). Rather, different types of expertise – not only technical – should be considered when analysing the vaccination debate.

This paper intersects the sociology of health perspective with science and technology studies (STS) allowing for the study of the role of vaccine-hesitant parents' expertise in challenging the primacy of scientific authority as well as the main models that are deployed to manage (public and individual) health. Specifically, the paper aims to understand the main elements that are involved in the relationship of vaccine-hesitant parents with science and scientific experts – including healthcare professionals. This study presents the results of an exploratory qualitative case study conducted in the Province of Trento (i.e., Provincia Autonoma di Trento) located in

the northeastern part of Italy. The research has been carried out in 2018, shortly after a national reinforcement of childhood vaccination obligations, which increased the number of mandatory vaccines and introduced sanctions for non-compliance. The study is based on participant observation and 26 interviews – 21 with organized vaccine-hesitant parents and 5 with physicians.

Considering childhood vaccines as technoscientific innovations to highlight the complex relationships between science, technology, and society, the paper first gives an overview of the main drivers of parental vaccine hesitancy. It then focuses on the role played by alternative expertise and specific vaccine-hesitant parents' approach to their children's health in guiding the vaccination decision-making process. Using case study data, the paper explores the role played by information-seeking for vaccine-hesitant parents, who actively engage in making their own research to build their expertise and make "informed" vaccination decisions; the elements that characterize the relationship of vaccine-hesitant parents with healthcare professionals; and the ways in which those parents perceive science and scientific experts. The study finds that hesitancy cannot be reduced to a set of anti-scientific positions; rather, vaccine-hesitant parents' criticisms are mainly directed at scientific experts and their paternalistic approach. Particularly, vaccine-hesitant parents perceive the doctor-patient and expert-citizen relationships as becoming increasingly weakened. This is mainly due to the social implications of the re-enforcement of vaccine requirements, the lack of recognition and legitimacy of vaccine-hesitant parents' concerns as well as the relevance of their expertise.

## 2. Parental vaccine hesitancy and vaccination decisions

Fears for adverse events following immunization (AEFI) are among the most cited reasons for either refusing childhood vaccines (McKee and Bohannon 2016; Facciolà et al. 2019) or anti-Covid-19 vaccines (Markovitz and Russo 2020; Salyer 2020). Trust plays a fundamental role in vaccination decisions and allaying fears about AEFI. Vaccine confidence can be influenced by trust in vaccine-related policies, in the products (i.e., vaccines and their components), the providers, and the infrastructure that supports such programmes (Goldenberg 2021; Larson et al. 2015). Vaccine confidence can also be influenced by trust in key actors – including scientific experts. The safety and efficacy of vaccines are additional elements that influence decisions on whether to be vaccinated and/or to vaccinate (Bucchi et al. 2022; Larson et al. 2018; Lazarus et al. 2020).

Parental vaccine hesitancy is "complex and multifaced" (Díaz Crescitelli et al. 2020, 43). As pointed out by Dubé et al. (2021, 177), the "state of ambivalence toward vaccination highlights legitimate doubts and concerns about vaccines", highlighting vaccine-hesitant parents' wish to discuss and engage with vaccine-related uncertainties (Kirkland 2012; Leach and Fairhead 2007). Political and health institutions, however, have not recognized that vaccine-hesitant parents address the vaccine safety issue from a different perspective, displaying individualized perception of risks that "makes the presence of rare but serious adverse events a safety priority rather than, as health officials see it, a reasonable risk" (Goldenberg 2016, 564). Vaccination scepticism is not constituted by a homogeneous front of parents opposed to vaccines – negatively labelled as "No-Vaxxers" (or "anti-vaxxers"). Instead, vaccine hesitancy is constituted by different "gradations of [vaccination] acceptance" (Streefland et al. 1999, 1709).

As highlighted by Reich (2016, 11), "we live in an age of personalization" in which "we see heightened efforts to personalize medical care to meet the desires and needs of the individual". Thus, many parents engage in what the author defined as "individualist parenting", i.e., involving a significant investment of time and energy in planning the best strategies to keep children healthy. This parental commitment results in increased attentiveness to children's needs as well as demands for more personalized institutional responsiveness (Reich 2016). The fact that vaccine safety has been demonstrated from a public health point of view is not considered sufficient evidence for parents who are concerned to know whether vaccines are safe for their own children (Goldenberg 2021). Thus, vaccine-hesitant parents adopt a "particularistic" perspective on children's health (Leach and Fairhead 2007) that leads them to carefully evaluate the current or potential impact of vaccines on their children's particular health condition. Consequently, in deciding whether to vaccinate their child and against which disease(s), such parents first consider their children's health history as well as their family health history. Furthermore, they evaluate the likelihood of their children getting a vaccine-preventable disease (VPD) and what the impact of the VPD would be. Vaccine-hesitant parents do not necessarily underestimate the potential negative consequences of VPDs. However, they think that vaccination is not the only tool for prevention and that institutions overestimate the risks of infections as well as vaccine efficacy (Blume 2006; Rogers and Pilgrim 1994). In this way, vaccine-hesitant parents often ask for an individualized vaccination schedule and refuse to vaccinate their children according to a national, one-size-fits-all immunization schedule (Dempsey et al. 2011; Klugar et al. 2021). As highlighted by Leach and Fairhead (2007, 51), this request can be considered part of a broader societal shift towards "more individuated [childcare] regimes adapted to the particularities of each child".

### 2.1 Parental reflexivity and alternative knowledge production

Studying the complexity of vaccine-related attitudes moves beyond arguments based solely on the safety and efficacy of vaccines (Widdus and Larson 2018). Indeed, in their research, Poltorak et al. (2005) highlighted that mothers' engagement with the measles, mumps, and rubella (MMR) vaccine is particularly influenced by experiential factors such as personal histories, childbirth events, and levels of sharing other parents' concerns. Experiential factors construct parents' "experiential knowledge" (Borkman 1976, 446) i.e., the "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others". Therefore, personal experiences, personal judgements and feelings become of primary relevance in defining what is true. To further examine this phenomenon, van Zoonen (2012, 57) introduced the concept of "I-pistemology" - i.e., "the self as the origin of all truth". According to the author, especially in situations of high epistemological uncertainty in which it is not clear whom to trust and what is true, one of the strategies that people can adopt to cope with this insecurity is to turn themselves into "an alternative source of knowing and understanding" (van Zoonen 2012, 60). More recently, Crabu et al. (2023) looked at the health-related beliefs of concerned communities and how their claims were (partially or totally) refused by scientific authorities during the Covid-19 pandemic. Crabu et al. (2023, 149) highlighted that the "refused styles of thought" are

constituted by experiential expertise used "to reframe the body in a process of self-care, thus validating a corpus of refused knowledge through direct personal experience". By applying demarcation strategies and narratives, "with respect to the prevalent biomedical paradigms", the concerned communities acquire "experiential epistemic autonomy". Experiential knowledge and expertise are thereby co-created, shared, and mobilized by concerned communities thus producing alternative ways and meanings to manage public and individual health.

As highlighted by several authors in the field of STS (Callon 1999; Turner 2001; Wynne 1996), different types of expertise can be both facilitated and/or hampered depending on the context considered. This is especially true in the healthcare field, which has led to the rise of alternative forms of expertise, based on the experiences and interests of a plurality of stakeholders – including parents. In the medical field, scientific expertise is not only technically oriented knowledge but also socially constructed knowledge (Epstein 1996; Kerr et al. 2007). Indeed, according to Jasanoff:

scientific knowledge, in particular, is not a transcendent mirror of reality. It both embeds and is embedded in social practices, identities, norms, conventions, discourses, instruments and institutions. (2004, 3)

Political decisions and policy strategies – such as those of vaccination campaigns and vaccination mandates – include several non-scientific factors. In her study, Carrion (2018, 321) highlighted a specific and alternative form of knowledge production based on the "social experience of motherhood". The author pointed out that it is important for vaccine-hesitant mothers to make informed vaccine-related decisions based on their own research. In these decisions, vaccine-hesitant parents carefully take into consideration their children's needs and make "independent decisions, based on their own knowledge and intuition" (Reich 2016, 72). This parental expertise should not be belittled: parents know their family history and health-related vulnerabilities, and both elements can play a "legitimate role in decision-making about vaccinations" (Cassam 2021, 6).

In this regard, the concept of reflexivity becomes relevant, understood as "the general capacity of late modern actors to reflexively consider their own health in light of medical knowledge proliferated in late modern societies" (Numerato et al. 2019, 85). Reflexive reasoning is thus included in citizens' decision-making processes about their own, or their children's, health (Giddens 1991; Miah and Rich 2008). Vaccine-hesitant parents can thus be seen as "reflexive patients", a concept that refers to "increasingly reflexive and decreasingly deferential citizens" (Martin 2008, 41). The increased reflexivity allows citizens both to deal with uncertainties originating from the advancements of scientific knowledge and the problematization of scientific knowledge (Beck et al. 2003). As noted by Kaufman (2010, 12), "parents reflexively practice and ponder an ethic of care and choice" based on their perception and evaluation of vaccine-related risks and according to their own criteria (Boholm 2003; Gottlieb 2016). Even if scientific expertise is requested, vaccine-hesitant parents do not blindly rely on it, thereby "living with the potential risk of vaccines and the anxiety of ever-partial knowledge" (Kaufman 2010, 12).

## 3. Research context and methodological frame

One of the strategies that governments can adopt to try to address a decrease in vaccination rates is a mandatory vaccination policy, mainly oriented towards childhood vaccination. Revised vaccination strategies, which have involved the adoption or strengthening of existing childhood vaccination requirements, have been introduced in many countries. Since 2015, in an effort to increase vaccine uptake rates, several high-income countries – such as Italy, France, Australia, and Germany – have adopted increasingly more coercive childhood vaccination policies (Attwell et al. 2021; Ward et al. 2018). Particularly, Italy was the first European country to introduce an increased number of mandatory vaccines for children up to 16 years of age (Law No. 119/2017).

Since the 1960s, Italy has adopted several approaches to vaccination governance: childhood vaccines were mandatory until 1998, while between 1999 and 2016 the distinction between recommended and compulsory vaccinations was progressively exceeded (Signorelli 2019). Until 2016 indeed, Italy adopted a "quasi-voluntary" vaccination policy in which sanctions for non-compliance were either rarely enforced (Attwell et al. 2018) or considered "low cost opportunities for refusers to 'purchase' non-compliance" (Attwell et al. 2021, 462). In 2001, after modifications to Title V (part II) of the Italian Constitution, regions were empowered with increased autonomy in health policy, leading to a great legislative fragmentation of vaccination strategies across the country. The situation has particularly changed with the introduction of Law No. 119/2017<sup>3</sup>, which requires an increase in the number of mandatory vaccines – from four<sup>4</sup> to ten<sup>5</sup> – for children between 0 and 16 years.

This Law faced strong opposition from families who did not want to fulfill these vaccination requirements; some felt the need to network, looking for support to advocate for their positions. Critics have mainly focussed on the penalties provided in this law. Those who do not comply with the vaccination plan must pay a fine (up to 500 euros) and children up to six years of age who are not (or only partially) immunized cannot attend public and private nursery schools or kindergartens.

An interesting case in the Italian vaccine-related legislative landscape is represented by the Autonomous Province of Trento. Unlike other Italian regions, including other autonomous regions, the Province of Trento approved resolutions that strengthened the sanctions already provided by Law No. 119/2017 for non-compliant parents between 2017 and 2018. While other regions, such as the Autonomous Province of Bolzano, adopted an approach that emphasized dialogue with parents, the Province of Trento adopted a more aggressive policy for compliance. Trentino's Provincial Resolutions No. 322/20186 and No. 547/20187 represent its approach: the first introduces the suspension of monthly economic benefits (called "service vouchers") for non-compliant families, while the second excludes children not fully vaccinated from summer camps. Furthermore, Trentino's political and health authorities have introduced the label "conforme" (compliant) and "non conforme" (non-compliant) to identify, respectively, children who have fulfilled their vaccination obligations and those who have (totally or partially) not done so. Thus, "No-Vax" and "non-compliant" labels have negatively labelled those people who have expressed their opposition either to vaccination practices or to vaccination mandates. This has generated social tensions between those who decided to vaccinate their children according to the national vaccination schedule and those who decided not to do so.

It is in this context that the following case study was undertaken. Conducted in the Autonomous Province of Trento (Italy) between February 2018 and May 2018, it focuses on a Free-Vax association – i.e., one that advocates for the freedom of choice in vaccination decisions. *Vaccinare Informati* is the only Free-Vax association in Trentino and since 2006 has organized and promoted events and public initiatives regarding vaccines and health. This association was selected for three main reasons. First, unlike other Free-Vax associations in Italy that tend to form specifically to oppose a particular vaccination or health policy (and are therefore likely to disappear shortly afterwards), *Vaccinare Informati* has been active on the territory well before the reinforcement of childhood vaccination obligations (Law No. 119/2017). Second, *Vaccinare Informati* has become a reference point for vaccine-hesitant families who need support in their vaccination choices (also) in other regions of the country. Third, given its long history in the promotion of freedom in vaccination decisions in Trentino and its openness to dialogue over the years, *Vaccinare Informati* has been recognized as an interlocutor by the provincial political authorities.

For the study, 21 semi-structured interviews were undertaken with members of the *Vaccinare Informati* association. Interviewees, over 18 years of age, were identified through snowball sampling (Barbour 2014; Given 2008). The sample was relatively balanced in terms of gender and educational level (Tab. 1).

Vaccinare Informati members	N
Gender	
Female	13
Male	8
Total	21
Educational level	
Tertiary (degree)	13
Secondary (diploma)	8
Total	21
Occupational sector	
Clerical	7
Education	6
Social and Healthcare	3
Specialized/technical	3
Blue-collar	2
Total	21

Table 1.

Socio-demographic characteristics and vaccination choices of *Vaccinare Informati* members (N=21), Trentino (Italy), 2018.

The study viewed vaccine-hesitant parents as a heterogenous group adopting a variety of vaccination choices. The widespread misconception that has characterized public debate and media communication both before and after the onset of the Covid-19 pandemic is that vaccination scepticism is constituted by a homogenous front of people opposed to vaccines – negatively labelled as No-Vaxxers. Contrary to this characterization, vaccine-hesitant people are a heterogenous category with differing levels of hesitancy towards one or all vaccines. Vaccine-hesitant people may decline certain vaccines but accept others, postpone a vaccination schedule, or accept vaccine(s) with reluctance. Table 2 shows the different vaccination choices vaccine-hesitant parents made for their children, ranging from partial vaccination to no vaccination.

Vaccinare Informati members	N
Vaccination choices	
All mandatory* vaccines for a child and some vaccines for the other(s)	2
All mandatory* vaccines for a child and none for the other(s)	2
Some vaccines for all the children	5
Some vaccines for a child and none for the other(s)	4
No vaccines	8
Total	21
* All mandatory vaccines before the introduction of Law No. 119/2017	

Table 2.

Vaccinare Informati members' vaccination choices (N=21),

Trentino (Italy), 2018.

The study also included the "specialist" view on the Italian vaccine issue with interviews with five doctors who have had experience with vaccine-hesitant patients. Particularly, these additional semi-structured interviews were conducted with four paediatricians (one of them is also a clinical researcher) and another, with a general practitioner endorsing and practicing homeopathy. All the healthcare professionals interviewed believed in the importance of child-hood vaccination as well as vaccines in general. However, the general practitioner was opposed to the national vaccination mandate and its sanctions and was therefore more aligned with the Free-Vax positions. The limited number of interviews with doctors was due to the difficulty of finding physicians willing to be interviewed. This was due to fear of exposing themselves to a controversial issue that was much debated in Italy at the time of the introduction of increased mandatory vaccines (Law No. 119/2017).

All interviewees signed the informed consent form, and all interviews were audio-recorded, fully transcribed, and analysed using Atlas.ti. Qualitative content analysis (Williamson et al. 2018) was performed. The interviews – conducted in Italian – were pseudonymized to protect the interviewees' privacy and the interview excerpts were translated into English.

# 4. "Awareness always has a price": Making informed vaccination decisions

Contrary to a widespread misconception, vaccine-hesitant parents do not lack information. Rather, these parents tend to consider trust in political and health institutions as passive, and that parental assessments and decisions made independently of the wider institutional context are more responsible and empowering (Hobson-West 2007). Indeed, vaccine-hesitant parents mainly adopt an individualist parenting approach (Reich 2016), investing time and energy in self-educating "to make informed decisions about their children's health risks" (Cassam 2021, 6). These elements clearly emerge from Olivia and Barbara's words:

Most of the people I have talked to who have vaccinated [their children] don't even know what they vaccinated [them] for, but this is not, in my opinion, because they are bad parents – absolutely not. However, I feel like I am more responsible than them because I know. Then maybe I am making the wrong choice; however, I have informed myself and I know what I am vaccinating for. (Olivia, *Vaccinare Informati* member)

And with these parents, talking about the uninformed parents... when you ask them, "But what sources of information do you have?" "Ah I have my paediatrician who told me to vaccinate, and I vaccinated" or, "My sister works in the medical field and she talked to some doctors who said it's right [to vaccinate]". And of course, being that we also have to keep informing ourselves and trying a little bit to figure it out, these are things that hurt you and make you angry because I can understand that a person who has delved into the topic of vaccination and is convinced, has a position that may even be radical. A person who in the end has not delved into the issue, who then comes to you and talks to you about uninformed [vaccine-hesitant] parents – it is really humiliating. (Barbara, *Vaccinare Informati* member)

Vaccine-hesitant parents tend to avoid mainstream media when searching for information about vaccines. Instead, they privilege their own research undertaken through alternative channels to the mainstream and the Internet, largely avoiding social media as a source of information. Television and newspapers are often considered providers of institutional positions and misinformation and therefore untrustworthy on the subject of vaccines.

No one questions whether what is said on television is real or whether there is some misinformation underneath; it is completely taken at face value. So, with the media, you are properly institutionalized to think in a certain way, and those who do not follow [this mainstream thinking] and do not buy everything that is said on television are categorized as nonconformists, No-Vaxxers, naturalists, in short, are considered to be people who are uninformed, who are ignorant, and who believe in Santa Claus, when in fact it is probably exactly the opposite. The media manage to do this: newspapers, television mainly... But television, in my opinion, is the worst. Television and the Internet are the ones that create as much misinformation as possible. (Alessia, *Vaccinare Informati* member)

When searching for vaccine-related information, vaccine-hesitant parents believe the web constitutes a more desirable source of information than traditional media. Indeed, the web is perceived by *Vaccinare Informati* members as a more "democratic" source of information from which it is easier to both verify the reliability of the information and delve into topics.

Rather, we inform ourselves perhaps by reading or choosing news in another way: the Internet is a bit more democratic, it is true that you can find a little bit of everything, however, you can find a plurality of information... and there is much more possibility for in-depth study because if I see an article that refers to a scientific journal, with an article published in a journal of a certain type, I can actually go and look at the sources. From what I'm told in a news report, how do I go and check the sources? (Tiziano, *Vaccinare Informati* member)

According to Brown (2008, 273), the Internet has led to the "globalization of medical knowledge" and "to the rise of increasingly clever patient". Clever patients or "informed patients" (Kivits 2004) increasingly search for and interpret health information independently, relying on a variety of health-related information sources. Hence, the Internet can be seen by vaccine-hesitant parents as a way to create some "distance from expertise" and at the same time "to enter into a meaningful dialogue with experts' authoritative discourse" (Bakardjieva 2010, 175).

Parents continuously reflect on the most relevant reasons in their vaccination decision-making process, i.e., the factors leading to vaccine-hesitant positions (Majid and Ahmad 2020). The decision to vaccinate does not necessarily imply the absence of vaccine-hesitant attitudes:

while non-vaccination or single vaccination requires a continued engagement to affirm the position taken, even parents who opt for MMR [vaccine] continue to learn and say they remain open despite having taken a decision that is irreversible. (Poltorak et al. 2005, 717)

From a moral point of view, parents may thus feel compelled to become more reflexive about their own vaccination decision-making processes. When parents have vaccine safety doubts, the "problem of freedom" arises, i.e., "the problem of the enactment of an ethic of self-conduct, of personal responsibility, in the realm of vaccine safety" (Kaufman 2010, 12; Rose 1999).

People [who comply with the law] prefer to look the other way because if they think it might harm their child – a certain behaviour, that is – a parental responsibility arises, it's hard to put it on one side... if a doubt crept in here, they would have an obligation to inform themselves, they would have to deal with a whole series of things that now are very heavy [to handle] such as an exclusion, fine, etc., as well as marginalization because that is also heavy [to bear]. (Giulio, *Vaccinare Informati* member)

As anticipated by Giulio's words, non-compliance comes at a cost when vaccination mandates introduce sanctions. The consequences of vaccination dissent are generally carefully considered by vaccine-hesitant parents in their decision-making process. Such parental reflexivity is an attitude particularly visible in Trentino. In this territory, parents who have decided not to vaccinate their children according to the national vaccination schedule must deal

with increased sanctions for non-compliance introduced by local authorities (e.g., the service vouchers suspension) in addition to the fines and exclusion of their children from preschool services already provided in national law.

Service vouchers are nothing more than the latest result of a doggedness here in the Province of Trento, not Bolzano in that with this legislation, the Province of Trento... could have made different choices anyway. Instead, it decided to follow the norm and, in some cases, has even made things worse... This a unique case in Italy, a unique case actually for two reasons: first, service vouchers exist only in Trentino; and second, a unique case in Italy because no one in any other region has ever dreamed of making a regulation worse than one that is already very tough anyway. (Bruno, *Vaccinare Informati* member)

The introduction of additional sanctions for non-compliance in Trentino has further accentuated *Vaccinare Informati* members' perception of a discriminating environment and increased social tensions based on vaccination status.

# 5. "There is no trust in doctors anymore": A weakened relationship between the doctor and the vaccine-hesitant parents

Vaccine-hesitant parents often have difficulties in openly discussing vaccination with their general practitioner or paediatrician. As highlighted by Blume (2006, 637), "vaccination may be voluntary in theory, but that is not how most health professionals treat it in practice" and vaccine-hesitant parents see the official vaccine-related information as designed to "induce conformity" rather than inform. Following the introduction of the Italian law on mandatory child-hood vaccination in 2017, both the parents and the physicians interviewed perceived a general loss of trust in the doctor-patient relationship. According to Sara, this relationship is perceived as paternalistic, a relationship in which unilateral communication does not allow dialogue.

There is no trust in doctors anymore... Then "you have to do this because that's just the way it is"; it doesn't work. (Sara, *Vaccinare Informati* member)

When seeking vaccine-related information, vaccine-hesitant parents often choose not to consult their children's physician because they think that an open, non-judgmental, discussion on the issue is not possible (Evans et al. 2001; Leach and Fairhead 2007; Yaqub et al. 2014). When scientific consensus over vaccines does not create trust, vaccine-hesitant parents "are ridiculed for raising concerns, questioning expert testimony, and taking seriously minority dissenting opinion" (Goldenberg 2021, 128). For example, Sara and Oriana's concerns – based on their children's health vulnerabilities – were not taken seriously or addressed properly by healthcare providers.

So many times, when I was summoned [for a doctor's appointment] for the children, to know why I was not getting the vaccines, I told them about my particular situation and

family history, and they didn't give me any answers and just laughed. Or they were joking about it. And honestly, this to me is an inhumane thing because I told them, "For you, it can be just one who can have an adverse reaction, for me that one is my whole life". (Sara, *Vaccinare Informati* member)

At the time of the birth of the second child, there was clearly a strong fear about facing [the same situation experienced with the first child] because there is certainly a genetic allergic predisposition with the first child and the second child was also born tending to be allergic – so, triggering or aggravating this problem was my primary concern. I said if there are already difficulties, you are going to stimulate or burden a two-month-old child, and you don't know what they are allergic to. Even a small amount of a substance is enough [to cause a vaccine adverse reaction]. Clearly, I felt responsible at that moment there. Since I had listened faithfully before to what they [paediatricians] advised, at this point I said let's stop for a moment and evaluate. (Oriana, *Vaccinare Informati* member)

Some of the interviewed doctors also perceived an increased tension in their relationship with parents because of Law No. 119/2017. Specifically, the reinforcement of childhood vaccination mandates has contributed to making the relationship of trust more fragile and difficult to build over time – especially with those parents more sensitive to the issue of vaccine adverse events.

And to me, yes I would love to see the vaccine requirement removed, but as a paediatrician, so that we can give ourselves [as doctors] a chance to get back to grounding our relationship in trust and bringing parents to a choice that is informed. And these requirements have not favoured us in that. (Maddalena, paediatrician)

Accordingly, some parents interviewed believe that, in part, this deterioration in the doctor-patient relationship has been exacerbated precisely by the law. Particularly highlighted by Elisa's words, there is a belief that most doctors have lost their professionalism because they have been forced to align with the law for fear of being disbarred by the National Medical Association's.

It [vaccination] should be a free choice made with your doctor, but doctors are deprived of their professionalism, they can no longer decide, they are afraid because they have seen that they have applied the fascist method of hitting one to punish a hundred. So, they [the authorities] hit some very prominent, very good doctors who have given their lives for patients... It's not that they don't want to, most can't. And so, we hope that it changes and that the doctor regains his/her professionalism and his/her way of acting in science and conscience. (Elisa, *Vaccinare Informati* member)

The deterioration of the doctor-patient relationship was perceived by interviewees also in the local vaccination hubs: pre-vaccination appointments seemed to be conducted "with the stopwatch in hand", and medical staff seemed unwilling to dialogue with parents to answer their questions. Indeed, many healthcare providers report difficulties in communicating with vaccine-hesitant parents, consultations that they perceive as unproductive (Wilson et al. 2020).

However, the great organizational strain on medical staff due to the new procedures and timelines required by Law No. 119/2017 was clearly acknowledged. This pressure on Italian healthcare workers, already overburdened by broader issues of personnel shortage in the healthcare field, was recognized not only by the doctors interviewed but also by *Vaccinare Informati* parents.

I've seen five children come in and out in the space of five minutes and one behind the other just in a continuous stream. So certainly, there is also work stress in the vaccination centres. (Davide, *Vaccinare Informati* member)

Then, in my opinion, the problem of our health care organization is that the paediatrician of free choice or the general practitioner has about 5,000 patients in the queue and cannot devote the right amount of time to those who are there... That's the big problem... and unfortunately people think that the doctor or the professional did not really listen to what they needed and so they tend to go in other directions. (Zoe, paediatrician)

The introduction of Law No. 119/2017 was followed by a general change in the approach to vaccination. According to *Vaccinare Informati* parents, this has been a step backwards eliminating dialogue between parents, healthcare providers, and local authorities, that had been built over the years in Trentino.

Both at the level of the Trentino Health Department and at the level of doctors who are part of the health care system, the stance taken is completely obtuse, and was different just a few years ago. It seems strange to me that in 2006 there was [...] a general tendency towards greater responsibility: it was seen as progress to have this freedom to choose and now, suddenly, everyone has had to or has chosen to change perspective and return to an approach of twenty-thirty years ago. (Tiziano, *Vaccinare Informati* member)

Furthermore, the doctors interviewed highlighted communication issues between local health institutions and parents, especially at those institutional events organized to communicate the changes introduced by Law No. 119/2017. According to the paediatricians Maddalena and Giorgia, during those events, instead of dialogue, there was a stand-off between citizens and authorities. Rather than addressing parents' concerns, a top-down communication of general vaccine-related information was delivered by the authorities.

At those events, they asked us [paediatricians] to go too, now I wouldn't know how to solve [the vaccine issue], but I realized that there is no dialogue: it's like two bulls clashing into each other. (Maddalena, paediatrician)

There was a stand-off there because whoever organized the meeting said what they had to say, they linearly said what they had to say and stopped... A lot of time was wasted in this communication talking about what disease it is, what happens with that disease, what the vaccine is like, etc... People didn't need to know these things or hear them repeated, people are there to understand. (Giorgia, paediatrician)

As highlighted by Gottlieb (2016, 158) "[vaccination] advocates focus on the population-level value of universal vaccination and critiquing fallacious claims about vaccine dangers". However, the fact that vaccine safety has already been demonstrated from a public health point of view is not sufficient to convince vaccine-hesitant parents to embrace the national vaccination schedule: parents are instead concerned to know whether vaccines are safe for their own children, based on their health history, in line with a particularistic perspective of children's health (Leach and Fairhead 2007).

In deciding whether to vaccinate their children and, eventually, against which disease(s), *Vaccinare Informati* parents first evaluate the likelihood their child will get a vaccine-preventable disease (VPD) and the likely impact of the VPD on that child. Furthermore, other relevant elements that vaccine-hesitant parents take into consideration in their vaccination decision-making process are the specific context in which they live, as well as their lifestyle. Rather than being a priori opposed to vaccines, vaccine-hesitant parents often ask for an alternative and personalized vaccination schedule; e.g., they may request a delay between vaccine inoculations or the use of monovalent vaccines instead of combined ones (Dempsey et al. 2011).

So, we have allowed ourselves to make this kind of choice, which is not necessarily everyone's choice or the one that has to be standardized for everyone. Just as in our opinion the preventive vaccine plan does not have to be standardized, neither does the non-vaccine plan. Because these are choices that have to be made with some awareness and by evaluating the whole picture: if a family has the opportunity to live with a particular [healthy] lifestyle, then they can choose to go with a certain [vaccination] approach; in other contexts the risk is different, and it all has to be evaluated differently. (Manuel, *Vaccinare Informati* member)

Do you make them [vaccines] mandatory? All right, I may be okay with that, but we administer them in a way that I think is suitable [for her children] because it doesn't change [if vaccines are inoculated in monovalent doses rather than combined ones]... The child then eventually turns out immunized, whether I gave him a six-in-one shot or whether I gave him six detached shots eh... So let me do it [monovalent vaccine] because I was able to do it until a year ago. (Noemi, *Vaccinare Informati* member)

As highlighted by Cairns et al. (2013, 1550), when trust in health authorities and their representatives decreases, it "undermines public perceptions regarding their legitimacy to lead public health strategy and policy". Specifically, vaccine-hesitant parents often perceive both the attitudes of healthcare providers and most of the scientific literature available on vaccines as particularly dissatisfying – especially when their vaccine-related concerns are not adequately addressed by scientific experts. In this context, vaccine-hesitant parents might adopt alternative medical practices or information sources (Goldenberg 2021; Peretti-Watel et al. 2015).

# 6. "Who is this scientific community?": Vaccine-hesitant parents' perception of science and scientific experts

Among the most relevant issues that emerged during the interviews with *Vaccinare Informati* parents are those of the perception of the role of science in society and of the relationship between the scientific community and citizens. In line with other research on this topic (Askvall et al. 2021; Lazarus et al. 2020), this paper has found that respondents do not distrust science. On the contrary, science is perceived as an important resource for society. Indeed, vaccine-hesitant parents emphasise that science does not work on its own; it is both managed by and a part of society. This is in line with a broader shift of focus from "science and society" to "science in society" (Bucchi and Trench 2021): in contemporary societies, the integration between these two spheres has increased to the point that "the development of present society cannot be conceived without the development of science and technology" (Schiele 2021,53).

I don't have a negative opinion of science [...], but science itself is an instrument of society and it is society that administers it; so it is society that gives meaning to what science says. (Barbara, *Vaccinare Informati* member)

The vaccine issue in the public debate has been characterized by a polarization of positions between science and experts on the one side and "anti-vaccine" and non-expert citizens on the other. As highlighted by Brunson and Sobo (2017, 46) "polarization feeds on itself, further strengthening the perception of a divide". According to *Vaccinare Informati* parents, this represents a clear attempt by part of the scientific community to recreate an "ivory tower", keeping a distance between what is considered scientific and what is not, and imposing an *ipse dixit* approach. The perceived separation between specialists and non-specialists arising from the adoption of a technocratic approach to science communication is especially evident around the issue of vaccines. In contemporary societies, however, the public rarely accepts technologies and innovations uncritically – both experts and non-experts want to, and have the right to, open and probe what Latour (1998) has referred to as "black boxes". Several authors (Callon 1999; Davison et al. 1991; Epstein 1995; Pols 2014) have focused on the role of "lay knowledge" – the counterpart to scientific or "expert" knowledge – in shaping and challenging scientific expertise, especially in health issues. According to Horlick-Jones (2004, 11), these are changes that "are taking place in the very production of knowledge".

Science arrogates and perches within a fortress of "I know and you know nothing", the distance from the population increases... When medicine, which is not a science but a practice based on scientific knowledge, tries to entrench itself inside a fortress made of "I know and you don't", it moves away from its own field of application, and therefore its destiny is certainly not a prosperous one. (Manuel, *Vaccinare Informati* member)

The parents interviewed for this study believe that science, as well as society, is divided on the vaccine issue: according to them, even within the scientific community, there are different factions that do not allow the issue to be addressed with the seriousness it deserves. According

to those interviewed, a large part of the community of scientific experts – mainly those who have been publicly visible in the media – have displayed arrogant attitudes toward citizens.

So, in the last two years, I've noticed a difference in the approach [of scientific experts] with people: "you haven't studied, stop, you don't know anything, enough, I'm in charge". From my point of view, this is called dictatorship, it's not called science. (Sara, Vaccinare Informati member)

Contemporary societies are described by Beck (1992) as "risk societies" in which people mainly face risks produced by industry and science - i.e., "manufactured risks". In this context, the main cultural focus on risk undermines conventional definitions of expertise: even if expertise might be considered authoritative and objective, "the nature of risk tends to undercut claims made about its authoritative understanding" (Horlick-Jones 2004, 110). As highlighted by Callon (1999), the core of the issue concerns the broader forced separation between science (specialists) and society (non-specialists). The concept of "expert" and what is considered "expert knowledge" are conventions that can change depending on the socio-cultural context. Thus, merely recognizing a role for expert knowledge does not oblige people to accept "the immaculate conception of expertise" (Turner 2001, 146). This is in line with the phenomenon of the "secularisation of the public image of science" (Bucchi and Neresini 2006, 39) whereby, while recognizing the usefulness and importance of science, people no longer accord it a special, quasi-sacred status. Vaccinare Informati parents perceive science as dogmatic and that it privileges mainstream scientific positions. They believe that science should be based on doubt(s), continuous research, and a plurality of positions, and they stress "the particularity and partiality of 'science" (Leach and Fairhead 2007, 24).

I believe that at the scientific community level, of published research, there is a plurality of ideas. The problem is that this plurality is denied at the level of communication. (Barbara, *Vaccinare Informati* member)

Inevitably three-quarters of the time a study comes along later that says the opposite of what was said in a previous study. And on this, I challenge people of science to say that this is not true. To pass science off as dogma is the death of science: science is not dogma, it is doubt and trying to figure out whether that doubt is true or not in order to take a step forward... And this is missing in the discussion of science, in my opinion, there is only verbal aggression against those who are not aligned. (Davide, *Vaccinare Informati* member)

The interviews conducted highlight that the contemporary problem "is not mistrust in scientists but, rather, a problem in deciding who the scientific experts really are" and, consequently, which expert can be trusted (Shapin 2004, 46). Indeed, parents and a doctor raised several doubts regarding the identification of the scientific community, and those who are part of it.

On television and in the media there are references to this scientific community and no one until now has been able to define its component parts. That is, who is this scientific community?... Who are they [its constituents]? (Bruno, *Vaccinare Informati* member)

They [mainstream scientific experts] think they have science behind them, but this science, this weird halo, who is it? I have scientific publications in international journals, I have many [academic] titles; however, I say, "I don't think the vaccine is the right thing". "Ah, [but] that's not scientific...". So, what the scientific community lacks is not the competence or the medical knowledge, but the commitment to criticism and self-criticism: they take for granted that they are the depositaries of scientific knowledge. (Paolo, general practitioner)

When science is recognized as having epistemic authority – i.e., a source on which people can rely to acquire knowledge – on a topic such as vaccination, it "may override all else" and significantly influence people's attitudes and behaviours on that topic (Kruglanski et al. 2005, 352). Furthermore, as highlighted by Suldovsky (2016, 420), "when science is selected or assumed as the epistemic authority... the deficit model is sure to follow", thus leading to top-down and unidirectional communication from "an epistemic authority (scientists) to a knowledge-deficient audience". However, it should be noted that people can trust science – its methods and principles – but not its institutions and their representatives (Bory et al. 2022; Huber et al. 2019). This is a matter of epistemic trust (Goldenberg 2021), i.e., trusting a person or an institution as a source of knowledge. This implies an epistemic dependence of trustors on the trustee's goodwill, thus exposing the former to the risk of being deceived or damaged (Wilholt 2013). Therefore, as in the case of vaccine, it is not straightforward to trust scientific experts when their actions and opinions can have a direct impact on people's own health (Crease 2004). Further, much of citizens' understanding of vaccinations is based on epistemic trust and having no or low trust in experts and their institutions can lead to vaccine hesitancy (Goldenberg 2021).

Public debates on scientific topics, such as vaccinations, often raise social, moral, and regulatory issues that go beyond scientifically based solutions (Scheufele 2013). Furthermore, due to the communication strategies of mass media (Bucchi 2000), the debate on vaccinations is often politically oriented rather than purely scientific. Indeed, despite vaccines often being portrayed as an incontrovertible and neutral public good, they are instead tied up with (bio) politics, "with struggles over status, authority and value" (Leach and Fairhead 2007, 2). The interplay and at times overwhelming plurality of quasi-scientific interests – largely driven by political and economic concerns – within the scientific community is one of the main concerns among the interviewees. According to Leonardo, this interpenetration of interests has privileged mainstream scientific literature in favour of vaccines, a unidirectional approach further entrenched by the lack of public funds allocated to vaccine-related research.

For sure, what I've seen in recent years is that, unfortunately, what dominates in this so-called scientific environment is not the so-called science because... unfortunately for many many years now, scientific research is funded almost exclusively by private interests – pharmaceutical companies in this case, or even by others... This means that over many years, a body of studies and scientific work in favour of vaccines has built up that is almost unbeatable, let's say, that is going in one direction. While before, when there was a little freedom and public funding, there were studies in both directions. (Leonardo, *Vaccinare Informati* member)

The role of the government in the vaccine issue – that should be that of "a desired regulator of the industry and protector of citizens" (Numerato et al. 2019, 92) – is often perceived by vaccine-hesitant citizens as piloted by pharmaceutical industries. Furthermore, the complex – and sometimes non-transparent – links between science, politics, and private organizations can increase the perception that scientists (as well as political and economic actors) are favouring their own interests at citizens' expense (Goldenberg 2021; Ivani and Dutilh Novaes 2022). In this regard, *Vaccinare Informati* members believe that there is a lack of transparency in the scientific field and that science is as corruptible as the political sphere.

There is a structural problem... that is given by the fact that scientific research is not done in a linear and clear way and, as you might think, that a researcher stands there and says, "Now I'll do an experiment and let's see where it takes me". They [the studies] start largely from the funding that is given and those who have the money are the big groups. (Tiziano, *Vaccinare Informati* member)

Today, science is perceived as both positive and "uncertain, sometimes irresponsible and above all bearer of particular interests" (Bucchi and Neresini 2006, 40). The increasing importance of the conflicts of interest issue is a feature that characterizes contemporary societies (Beck 1992). The issues raised cannot be merely reduced to an anti-science stance: critics of unethical pharmaceutical company practices – such as obscuring data or non-publication of negative results, as well as their influence on the medical and political sector, have been reported on in the literature (Angell 2005; Gøtzsche 2013; Sismondo 2018). Furthermore, the strong presence of economic and political interests in guiding scientific research is part of the broader scientific debate on "research integrity" (Ampollini 2018)<sup>10</sup>. Scientific institutions and their representatives cannot simply assume that "they should be trusted; instead, trust must be earned and maintained" (Goldenberg 2021, 170). When institutions and their representatives insist on promoting the narrative of a value-free science, scientific expertise and authority can be compromised rather than legitimized (Kitcher 2011a, 2011b; Latour 2015).

### 7. Discussion

This paper has presented qualitative data collected during an exploratory case study conducted in Trentino (Italy) on a group of organized vaccine-hesitant parents in 2018. Particularly, the paper focused on vaccine-hesitant parents' perception of the science and society relationship following the enforcement of Italian childhood vaccination mandates (Law No. 119/2017). The new childhood vaccination requirements have impacted those who do not comply with the mandates, especially vaccine-hesitant families in Trentino, where local authorities have adopted a more intransigent approach to non-compliance, increasing the sanctions already provided in national law. The study integrated the perspectives of vaccine-hesitant parents with the perceptions of a group of physicians on the introduction of mandatory vaccination and its implications for the doctor-patient relationship.

The analysis of Trentino's case study highlighted four main issues. First, vaccine-hesitant parents' relationships with (health and political) institutions and scientific experts have deteriorated due to the (total or partial) absence of an open and constructive dialogue. Particularly, trust and communication challenges increased following the introduction of Law No. 119/2017. Such deterioration is also evident in doctor-patient relationships. Indeed, according to both the parents and physicians interviewed, mandatory vaccination and its sanctions have further eroded the dialogue that had been built over the years between vaccine-hesitant parents and paediatricians. Since the introduction of the law, Vaccinare Informati parents perceived a change in their relationship with healthcare professionals when addressing the vaccine issue, a relationship now guided by paternalistic and unilateral communication. However, vaccine-hesitant attitudes emphasize "legitimate doubts and concerns about vaccines" (Dubé et al. 2021, 177), which should be recognized as such. These doubts and concerns should be carefully considered not only by healthcare professionals but also in the design of public health interventions. This implies a change in perspective that might allow vaccine-hesitant parents to be recognized as "exemplars of medically engaged patients, even if not necessarily compliant ones" (Gottlieb 2016, 160). Rather than being guided by ignorance and lack of education, vaccine-hesitant parents are continuously searching for information and questioning scientific experts and how vaccine safety is promoted. In line with Carrion's (2018, 320-321) research, the vaccine-hesitant parents interviewed in the case study are experiencing the "paradox of patient advocacy": even if the "critiques of the social and political practice of science also reflect dominant critical and postmodern perspectives" and are generally recognized as valuable in other health contexts, vaccine-hesitant parents' advocacy is often harshly criticized and marginalized.

The second issue highlighted by the case study is the contrast between compulsory vaccination on the one hand and parents' demands for freedom of choice and exemptions on the other. This contrast is not based on divergent values: it stems from a different interpretation of the same value (Zuolo 2013) - i.e., a different perception of what guides and should guide individual and collective health practices. Vaccine-hesitant parents are particularly concerned about monitoring their children's health and adopting health-related practices - including vaccination – that are highly personalized. This approach is in line with the broader shift toward increased personalization of medical care. Within this perspective, vaccine-hesitant parents should be recognized as engaged and reflexive patients (Numerato et al. 2019), rather than problematic and disregarded interlocutors. This implies the need for a critical examination of the standard definition of a "good patient" as the one who complies without questioning scientific expertise (Gottlieb 2016, 160). However, vaccination campaigns that support the introduction of vaccination mandates are often based on the assumption that compliance is the single correct public response to health communication strategies. This implies a loss in the variety of public responses (Manyweathers et al. 2020). It also implies that those patients that are not fully compliant will either be ignored or easily misinterpreted (Davis et al. 2015). By rejecting or deriding vaccine-hesitant parents' concerns, the media, and other key actors – such as policymakers, scientists, and healthcare professionals – have often contributed to fuelling the vaccine hesitancy phenomenon (Goldenberg 2021; Ivani and Dutilh Novaes 2022; Navin 2015).

Third, the case study results show that vaccine-hesitant parents interviewed trust science and the scientific method. However, what is contested by these parents is the authority of

scientific experts - especially those who were visible in mainstream media - and their institutions. On the vaccine issue, Vaccinare Informati's members believe that the scientific community lacks transparency regarding its members, existing conflicts of interests (political and economic), and research integrity issues. Furthermore, according to these vaccine-hesitant parents, the scientific community is detached from society, and this is further exacerbated due to a dogmatic top-down communication that does not allow dissent. Several authors (Fischhoff 2012; van der Bles et al. 2020) highlight that, usually, scientific experts – especially those advising public policymakers (Moore and Mackenzie 2020) - do not publicly communicate the uncertainty related to their findings. Indeed, the underlying assumption is that scientific experts need to provide certainties to the public to maintain authority and credibility. On the contrary, "this lack of transparency could potentially compromise important decisions people make based on scientific or statistical evidence" (van der Bles et al. 2020, 7672) - including vaccine-related decisions. The case study shows there is still a long way to go for science, scientists, and healthcare professionals to get closer to vaccine-hesitant citizens. As highlighted by several authors (Brunk 2006; Goldenberg 2021; Wynne 2006), citizens' opposition to science-based policy is often explained following the deficit model approach. Indeed, policymakers, healthcare practitioners, and scientists often see citizens as passive knowledge recipients rather than "exchange partners" whose opinions and concerns deserve to be considered (Goldenberg 2021; Ivani and Dutilh Novaes 2022, 54). Hence, there is still a need for a:

shift to a model of knowledge co-production in which non-experts and their local knowledge can be conceived as neither an obstacle to be overcome... nor an additional element that simply enriches professionals' expertise... but rather as essential for the production of knowledge itself. (Bucchi 2008, 68).

Fourth, this case study highlights the need for an improvement in the dialogue between institutions and vaccine-hesitant parents' associations. As Ceva (2013, 71) points out, one of the priority challenges facing democracies is the "reconciliation of minority instances of dissent". In contemporary societies, highly complex issues - such as those involving vaccines - are increasingly evident, challenging the current forms of political decision-making and democratic representation as well as how expertise is understood and defined. Political, health and scientific institutions should maintain an open dialogue with vaccine-hesitant parents and, especially, with the associations that represent them. Indeed, through their members, these associations can reach all those individuals who have doubts about vaccines and/or vaccination policies either directly or indirectly, offering different types of support to the vaccine hesitant. Involving these associations in the institutional discussions is important to fully recognize, understand, and try to address the doubts and concerns of vaccine-hesitant citizens. Involving citizens – or the associations that represent them – regardless of their positions on the vaccine issue could mitigate the social divisions currently exacerbated by a dualistic and simplistic division of the vaccine debate. When dealing with the vaccine hesitancy issue, institutions need a science communication strategy that is capable of going beyond paternalistic reassurances about the safety of vaccines and can consider the heterogeneity of attitudes that constitute the vaccine hesitancy and the relevance of alternative (parental) expertise.

### **Notes**

- <sup>1</sup> www.who.int/news-room/feature-stories/ten-threats-to-global-health-in-2019.
- <sup>2</sup> The WHO (2019, 2) defines an adverse event following immunization (AEFI) as "any untoward medical occurrence, which follows immunization and which does not necessarily have a causal relationship with the use of the vaccine. The adverse event may be any unfavourable or unintended sign, an abnormal laboratory finding, a symptom or a disease".
- <sup>3</sup> Law No. 119 of 31 July 2017, published in the Official Gazette No. 182 of 5 August 2017. This regulatory intervention is part of a broader national plan National Plan for Vaccine Prevention 2017-2019 and international strategy i.e., the Global Plan for Vaccination 2011-2020 and the European Vaccination Action Plan 2015-2020.
  - <sup>4</sup> Mandatory vaccines from the 1960s to the 1990s: anti-diphtheria, anti-tetanus, anti-polio, anti-hepatitis B.
- <sup>5</sup> Mandatory vaccines starting from 2017 (in addition to those required prior to 2017): anti-measles, anti-rubella, anti-pertussis, anti-mumps, anti-varicella, anti-*Haemophilus influenzae* B.
  - <sup>6</sup> Resolution of the Provincial Council of Trento no. 322 of 2 March 2018.
  - <sup>7</sup> Resolution of the Provincial Council of Trento no. 547 of 9 April 2018.
- 8 The Autonomous Province of Trento (2016) Vaccinare informati, appello ai consiglieri provinciali. Available at: <a href="https://www.consiglio.provincia.tn.it/news/giornale-online/Pages/articolo.aspx-?uid=178481">https://www.consiglio.provincia.tn.it/news/giornale-online/Pages/articolo.aspx-?uid=178481</a> (retrieved July 25, 2022); The Autonomous Province of Trento (2018) Libera scelta vaccinale: i comitati dai consiglieri provinciali per rilanciare la battaglia. Available at: <a href="https://www.consiglio.provincia.tn.it/news/giornale-online/Pages/articolo.aspx?uid=179553">https://www.consiglio.provincia.tn.it/news/giornale-online/Pages/articolo.aspx?uid=179555</a> (retrieved July 25, 2022).
  - <sup>9</sup> Federazione Nazionale degli Ordini dei Medici Chirurghi e degli Odontoiatri (FNOMCeO).
- <sup>10</sup> Research Integrity refers to research characterized not only by the sharing of common working principles and by the presence of virtuous and positive ethical attitudes on the part of those who conduct, evaluate and fund research but also free of misconduct (such as plagiarism and falsification of data).

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