



Original article

The importance of the patient voice in vaccination and vaccine safety—are we listening?

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ABSTRACT

Much has been written about the patient–physician relationship over the years. This relationship is essential in maintaining trust in the complex arena of modern diagnostic techniques, treatment and prevention, including vaccines and vaccine safety. However, a great deal of this material was written from the viewpoint of clinicians and academics. The patient voice may be positive or negative, fragmented or complex. Information sources are weighed and treated differently, according to the value system and risk perceptions of the individual. In post-trust societies, when people have less confidence in health authorities, communication needs to be more than a paternalistic top–down process. Notions of empowerment and individual patient choice are becoming crucial in medical care. The ‘voice of the patient’, which includes healthy individuals receiving vaccines, needs to be heard, considered and addressed. With respect to childhood immunizations, this will be the voice of the parent or caregiver. The key to addressing any concerns could be to listen more and to develop a communication style that is trust-based and science-informed. Regulatory agencies are encouraging clinical and patient-reported outcomes research under the umbrella of personalized medicine, and this is an important step forward. This paper attempts to reflect the paradigm shift towards increasing attention to the patient voice in vaccination and vaccine safety. **D. Holt, CMI 2016;22:S146**

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Introduction

Vaccination remains one of the most efficient tools for reducing the burden of infectious diseases and safeguarding health. However, there have been concerns about vaccine safety [1], which

may have an impact on vaccine acceptance. Vaccines are obligatory in many countries and recommended in others; hence, they are managed in a paternalistic manner. But patients and vaccine recipients have the right to make informed decisions. We are also living in a ‘post-trust’ environment [2,3], which means that the public no longer puts faith in the regulators or industry without questioning. It is not only the voice of the expert that is heard. Information can be disseminated through social media quickly and globally, with no checks on accuracy or on how this information may be used or interpreted [1,4].

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The public perceives risk differently from experts, and these differences may contribute to increasing vaccine hesitancy. Healthcare professionals (HCPs) can play a key role in vaccination and to do so, need to develop risk communication strategies that build trust.

This includes active listening techniques, to understand how others are assessing and perceiving risk, and to use this information to encourage better informed decisions.

This paper attempts to reflect the paradigm shift towards increasing attention to the patient voice in vaccination and vaccine safety and looks at how listening to the patient voice is key in any risk communication strategy.

There is a need to develop proactive risk communication strategies that work both ways, that is to say build up trust between medical experts and patients, and vice versa. Patients are not experts in the field of vaccines or risk assessments. Communication needs to be clear and concise, without complicated jargon and allowing questions and seeking feedback regularly. HCPs need to hear the patients.

The patient may voice subjective concerns and perceptions. Experts who understand and address these concepts will be able to ensure that important messages are not lost or 'lingering in the air' causing confusion.

Regulatory agencies are encouraging patient empowerment; for example, the European Medicines Agency is providing direct access to information for those who request it [5]. This approach provides additional transparency, which can help to build trust [6]. Recent work by Scherer *et al.* assessing the effect of safety information, showed that a concise summary can be useful, but too much detail (i.e. the detailed version of the Vaccine Adverse Reporting System) may have an adverse effect on vaccine acceptance [7]. Vaccine information is often technical, complex and difficult for a layperson to interpret, but if HCPs accessed this information to update their own knowledge, it could subsequently be used in two-way discussions with patients.

Meeting the objective of proactive communication requires going beyond information disclosure and forging a true alliance between vaccine recipients and/or their parents, patient organizations and HCPs [8,9]. Stronger individual and institutional relationships may be the right avenue to maintaining or restoring trust in public health and regulatory agencies, through which evidence-based vaccine safety information is delivered [10,11].

It is recognized that the 'patient voice' is a complex and far-reaching subject that can only be covered as an overview in its entirety. It may help to remember that both HCPs and patients share a common goal: to prevent illness while maintaining health. Avoiding unnecessary conflicts due to misunderstandings and establishing what Fischhoff and Scheufele call 'fewer but better conflicts' [9] will help to mitigate the polarizing effects of 'vaccine controversies' while maintaining a stable line of communication between patients and HCPs.

Who are the patients and what influences the patient voice?

The term 'patients' in this article extends to vaccine recipients and/or parents of vaccine recipients when the recipients are children. They are identifiable partners in the vaccine debate because they are recipients of a medical intervention, even though most vaccine recipients are healthy. In practice, patients may be exposed to many different vaccines, as either adults or children, and may speak on their own behalf or on behalf of patient organizations. As a consequence of different patient guises, a wide range of voices may be heard.

The patient voice will be influenced by various individual filters and perceptions. Psychometric risk studies of risk perception

identified a set of variables to help explain how people perceive risks, demonstrating that people worry up to a thousand times more about involuntary risks (for example being forced to live next to a cell phone tower) compared with a voluntary risk (e.g. using a cell phone), and accept more easily risks that they feel in control of (e.g. driving a car) compared with those they feel not in control of (e.g. being flown in an airplane). They also showed that people worry more about unfamiliar risks (e.g. bird flu) compared with familiar ones (e.g. seasonal flu) and are more concerned about high-kill-size risks (e.g. airplane accidents) versus low-kill-size ones (e.g. car accidents) [12,13].

Specific to vaccine-risk perception, early accounts suggested that vaccines were perceived as only moderately unknown or dreaded. People's perceptions of vaccines were comparable to those for aspirin as opposed to antibiotics or DNA technology [13]. With the rapid advancement of vaccine research and development, as well as manufacturing technologies, this may have changed.

Specific to health and illness, key perception drivers include, for example, the high/low prevalence of a disease [14], perceived risk frequencies, availability and comprehensiveness of information, perceived dilemmas and ambiguities regarding how to interpret information, and the consequences for decisions to vaccinate or not, in addition to freeloading versus altruistic feelings [15–18]. Personal views and choices may be further influenced by levels of confidence and trust in institutions, complacency and, sometimes, personal convenience [19,20].

Attitudes, beliefs and behaviours that indicate concerns about vaccine safety have been shown to contribute substantially to under-immunization in the USA [21]. Studies by Flynn and Ogden [21] and by Downs *et al.* [22] on vaccination showed how parents are trying to take into account complex and contradictory concerns as they have mixed feelings about the medical profession and the media – for example when taking into consideration the risk of the measles, mumps, rubella (MMR) vaccination versus the risk of related illnesses [21]. These studies also highlight the concerns that parents may have in deliberating about vaccination, and it was noted that if health workers understand the parents' concerns, it is easier for them to address these concerns directly and help patients to make better informed decisions [22]. The studies in MMR vaccination also showed how past vaccination histories play a role in the decision-making process. If healthcare practitioners can address the concerns at the early vaccination time slots, this will benefit the uptake rate for later vaccination schedules [21].

Finally, these studies illustrated the gap between concerns identified among parents—i.e. for adverse and longer-term effects—and the confidence among experts in the safety of vaccines [21,23].

Fostering two-way communication partnerships: the central role of the HCP

The physician–patient relationship has been much discussed in modern medical literature and according to Goold and Lipkin it is the subject of some 8000 articles [24]. The essence of the relationship has a direct correlation with quality of care as a central feature of modern health care, which enables direct risk communication [4,24,25]. A large European survey ($n = 5648$) confirmed that people expect individualized safety information to be communicated to them and that HCPs are seen as the main trustworthy source of information [26].

The role of HCPs is essential in a patient/healthcare relationship. Downs *et al.* pointed out that many parents lack basic knowledge on how vaccines work and find the standard information provided unhelpful [22]. He also noted that those with the highest need seem to be the most vulnerable when it comes to confusing information

[22]. Again, the ability to listen to patients and to understand their specific needs will help the HCP bridge the knowledge gap for these parents, who will then be better equipped to make informed decisions.

Another survey among parents of healthy children has shown that an intact patient–doctor relationship is a key factor contributing to vaccine acceptance [25,27]. These research outcomes indicate how HCPs could develop ways to communicate with patients on an individual level. Developing personalized communication strategies, which may involve narratives and metaphors, requires that physicians have sufficient time to listen, paired with the knowledge and communication skills to adequately address the concerns raised during the conversation [2]. Physicians who are able to identify with the patient's own perspective of their condition may be better equipped to offer the opportunity for open discussion and bilateral communication [28].

Talking and listening to patients seems like common sense but perhaps the fact that it remains the subject of research highlights that the communication gap between the doctor and patient still exists despite all that has been written. Patients want their voice to be heard—on the subject of vaccination as well as on their medical conditions—and therefore one needs to explore what the barriers are to effective communication. In the followings section we will identify several such barriers and potential solutions.

The internet—‘friend or foe’?

The Internet could be either a friend or foe with regards to patient education and empowerment [29]. HCP are using electronic resources and digital tools to keep in touch with patients, to send appointment reminders, and to provide online support and educational materials [29–34]. Digital two-way communication systems have also been used to allow patients and physicians to report toxicities and suspected adverse events [35,36]. Consensus protocols have been developed to study the use of mobile health tools for improving health and health services [37,38].

The impact of vaccine-related websites and social media on public perceptions of immunization is well-documented [39–42]. It is evident that internet sites are among the most commonly used information sources on vaccines and vaccine safety today [43–45].

This could be viewed as a sign of interest and active participation in vaccine prevention. Concern arises however from the fact that the initial choice of search terms when researching a topic online, will profoundly influence and potentially bias the results [44,46–48]. A number of studies have also investigated the role of different languages when searching the web, which, depending on the topic, may be substantial [49–53]. To this end, the Global Vaccine Safety Initiative and WHO have recently released a list of websites with reliable vaccine-related information in 12 languages [54].

Although the content and quality of vaccine-related online resources has been better understood and categorized in recent years, the commentary sections in social media have given the stage to extreme positions and rumours [41,55–57]. On a positive note, online platforms may also provide a unique opportunity for healthcare professionals to gain a better understanding of concerns and fears that may remain unspoken during personal interactions with patients [58–60].

Time constraints and organizational challenges

Unquestionably, time constraints are common in the modern healthcare system [61]. Consultations in general medicine and paediatrics are brief, allowing little time to discuss the rationale behind vaccine recommendations or to assess perceptions of risk.

Doctors in the UK have advocated for consultations to be increased to 10 minutes to allow sufficient time for health promotion to be included [62]. A review carried out in the UK in 2002 demonstrated the benefit of longer consultation times, in that general practitioners were more likely to include lifestyle advice and preventive activities [63]. However, most consultations in Europe last 10 minutes at most, as a result of resource restrictions, limited budgets and personnel [63]. With constraints on resources, how can an increased time be allocated to individual patients? Future studies should explore the cost-effectiveness and health benefits of in-depth consultations regarding the benefits and risks of vaccine prevention.

HCPs as role models

Lack of time is not the only barrier to listening to the patient voice. The attitude of the physician to their own health and knowledge in the area of vaccinology must be taken into account as it will probably influence vaccine acceptance. There is evidence to suggest that patients are more likely to be compliant with vaccine recommendations if their doctor has also been vaccinated [64]. Knowledge is another key factor, for example, during the drop in MMR vaccine uptake in the UK, nearly 20% of general practitioners stated that they had not read the material provided by the health authorities and another 30% stated that they had not received it [65]. Educating doctors with regards to factual knowledge, and communication skills will encourage them to be vaccinated themselves are therefore go hand in hand with patient compliance.

The final section of this article will focus on strategic approaches to effective vaccine communication and possible solutions for the challenges outlined above.

Criteria for effective listening and communication skills

First, the communicator needs to be well-informed and risk communication should be based on accurate scientific data. A promising benefit of the digital revolution with regards to improvements in healthcare is the emergence of big data, i.e. the possibility to capture, store and analyse numerous data items per patient, facilitating precision medicine [66]. However, the information needs to be presented in an easily understandable format not to overwhelm the patient. The HCP should be aware of and counteract any concern that, in this increasingly technological healthcare environment, the patient voice may matter less.

What will be important is how patients perceive that the HCP is listening, and that behind every piece of data there is a person. If this can be accomplished, HCPs may be able to deliver a risk communication style that enables a patient to feel comfortable around any informed decisions that they may take for themselves and their children.

Second, HCPs need be effective communicators. Modern communication tools offer new avenues to help effective communicators to achieve their goals. Text or chat messages for example, can provide a quick method of communication, which can reach adolescents and/or large numbers of individuals. However, these messages may not be automatically accepted or trusted and may compete with other sources of information. It may require building trust first by encouraging direct interaction with HCPs, who also need to acquire the knowledge and communication skills to adequately address the concerns that may arise [2].

Listening to the concerns is an important part of the process before additional questions are asked to understand the problem. A two-way communication will enable feedback to be received and demonstrate that the patient's feedback is welcome and actively encouraged by the provider. An interactive chat or text message

campaign could be effective in providing vaccine education and prompting patients to converse directly with their doctors and peers about vaccines and vaccination. As a service to the user, text prompts and chat-rooms could increase the likelihood of timely vaccination [67]. In a recent study, SMS queries were used to ask vaccine recipients whether they had experienced any adverse event following immunization. More than 70% of patients responded by SMS with the data received in near real-time [68].

Finally, effective communication needs to account for the central role that patient organizations should be playing in the HCP–patient dialogue. Certain health messages may be enforced through peer-to-peer communication among parents and patients. In the past, patient organizations have raised concerns that the patient voice is not always heard. For instance, it often seems to be excluded from biomedical research and the drug development process, as well as from the scientific literature. Patient diary cards, as they are used in some clinical trials, are one step in the right direction. The patient is encouraged to convey their subjective well-being, unfiltered and encouraged by the HCP.

More fundamentally, patient representative networks offer the unique opportunity to provide feedback regarding symptoms, treatments and the effectiveness of public communication strategies. This may take the form of *patient research partnerships* [69] and other initiatives where advocacy groups and others non-governmental organizations sit together with industry and research agencies [70].

Context matters: listening to the patient voice in different geographic regions of the world

Vaccination policy and public opinion about vaccines and vaccination differ significantly in different parts of the world. In some countries, vaccination is compulsory, whereas in others there is an increasing level of shared decision making with growing numbers of patients refusing to vaccinate [71]. It is therefore not possible to develop one single strategy or guideline that would be applicable to all geographies [72,73].

Even within the same region, cultural belief systems and religious orientations may differ between the HCP and the patient, and both may be heavily influenced by culture/history, and by religious and political beliefs. At the same time it is important that some public health messages are harmonized across different parts of the world, as evident during recent epidemics and pandemics.

When shifting towards the patient voice, it will be useful to consider mediating religious and other beliefs through trusted individuals in an active dialogue to bridge differences and develop two-way communication. Two brief case studies illustrate the lessons that can be learned from in-depth analysis of challenging situations globally (see *Textboxes 1 and 2*). Clear and flexible communication strategies for HCPs to undertake effective discussions with patients are key to building partnerships around the topic of vaccination [2,74].

Making it happen: strengthening the physician–patient relationship to bridge the communication gap

It is important that HCPs are trained to communicate in a language that is clear, comprehensive and devoid of any highly specialized medical terminology. In terms of context, HCPs should learn to encourage patients to express their concerns and to be open to the fact that the patient voice may also be influenced by the opinions of peers and family members. A solid, evidence-based message must be provided consistently to re-emphasize key messages from previous communications, ideally in repeated interactions and an ongoing dialogue with the patient [75].

Textbox 1

Lessons learnt from vaccine refusals in Nigeria—a case study

A recent study by Ghinai *et al.* [81] describes the boycott of the oral polio vaccine in 2003 by five northern Nigerian states identifying several key factors that motivated vaccine refusal among prominent religious and community leaders. The study highlights that ‘individual-centric politics’ and the views of high-profile figures were fundamental drivers of the boycott. The views held by religious and ethnic minorities and of local opinion leaders opposed those of global health stakeholders, including UNICEF and WHO as well as the Federal government of Nigeria, who together were responsible for procuring and delivering the vaccine. The boycott was finally overcome by careful diplomacy; however, concerns remained within some northern Nigerian communities who did not feel ‘listened to’ and this delayed the complete resolution of the boycott [82].

The impact of paediatrician behaviour on vaccine acceptance has been intensely studied by Opel *et al.* [76,77]. Video surveillance of patient–physician encounters allowed the researchers to categorize and score different physician behaviours during vaccine conversations [76,77]. A first interventional cluster randomized trial aimed to assess the impact of physician-targeted communication training on parental vaccine hesitancy and physician self-efficacy. The impact of the intervention was however minimal, which may in part be attributed to a limited

Textbox 2

The measles vaccination campaign following Ebola outbreaks in Liberia—a case study

In Liberia, community engagement was key in the latest integrated measles and polio vaccination campaign, which took place countrywide from 8 to 14 May 2015 for all children aged 5 years and younger. On 9 May, Liberia was declared Ebola-free. During the EBOLA epidemic, the health system had virtually collapsed, routine immunization was largely suspended, leading to gaps in herd immunity [83,84]. Throughout the country, social mobilization teams from UNICEF, WHO, Red Cross and other non-governmental organizations informed people about the campaign allowing them to voice any concerns that they may have about vaccination. Those who were afraid, were actively listened to. Knowledge was improved, fears were dispelled and false rumours debunked. In order to allow close contact with vaccine recipients, the teams went to remote places, engaging community leaders, religious leaders, women and youth groups. Contrary to polio-only vaccination campaigns in the past, where every household had been visited by a vaccination team, this time clinics were the focal points of administering the vaccinations. To increase acceptance, the vaccination campaign was combined with a non-vaccine public health intervention, a de-worming campaign (Figs 1 and 2). The campaign co-administering measles and oral polio vaccine was perceived as a great success. The countrywide coverage rate for oral polio vaccine was 82% and 80% for measles.



Fig. 1. Polio vaccination campaign during the aftermath of the Ebola epidemic in Liberia.

sample size and duration of study [78]. More research is needed using standardized scores and interventions in a variety of settings.

Active listening skills include both verbal and non-verbal communication. Techniques that may be applied are also of use in clinical practice. Physicians are not unfamiliar with the core competencies required to communicate sensitive information to patients (e.g. when conveying bad news such as a chronic illness or cancer diagnosis). The focus on active listening skills is particularly important when vaccines are discussed, representing long-term preventive decisions in healthy individuals as opposed to emergency interventions in acutely ill individuals.

How to communicate effectively is increasingly taught in medical schools and during continuing medical education; University College London for example, has established a Clinical Communications Unit offering undergraduate courses as well as individual training for postgraduate trainees and senior staff. Similarly, novel curricula now include bed-side training and vaccine communication with parents and patients under supervision [79]. This approach should be expanded to ensure that medical students are aware of patients' perceptions of benefit and risk. This is important because experts and non-experts tend to perceive risk differently [12]. Students should acquire techniques to understand patient perceptions and how (mis)perceptions can be changed. They should learn to use adequate communication skills when presenting scientific facts concisely while remaining able to listen to the views presented by the patient. One promising avenue has been explored by decision scientists at Carnegie Mellon University who adopted a so-called *mental model approach* to identifying patterns of beliefs regarding vaccination [22]. This approach entails a formal analysis of the beliefs of experts and lay people, followed by interventions that improve lay understanding and decision making [80]. After characterizing the scientific mechanisms that parents were expected to understand (both in terms of risk and benefits) open-ended interviews were used to reveal parents' mental models of these processes. One next step would be to develop risk communication material that bridges the gap between the scientific and lay conceptions. Teaching students and young doctors to listen may always be encouraged through positive identification with role models (see [Textbox 3](#)).

Textbox 3

How young doctors may learn to listen to the patient voice in vaccine safety



Fig. 2. Measles and polio vaccination campaigns combined with a non-vaccine intervention.

Healthcare professionals have the most important influence on parental vaccine decisions [74]. Teaching healthcare professionals clear and flexible communication strategies and ensuring clear referral pathways are the keys to addressing concerns about vaccination [85]. Medical students and young doctors are affected by public opinion, not unlike their peers. Training students to become competent vaccine consultants includes training in perceptive communication, i.e. the ability to listen carefully rather than to 'talk at' the patient.

It has been shown that the degree of formal training in vaccine safety has a direct impact on the quality of vaccine safety reporting [86]. Experience has shown that vaccinology may best be taught by infectious disease specialists who need to be proficient in infectious disease epidemiology, immunology, virology and microbiology as well as vaccine safety research and communication.

Regulatory and public health implications of immunization programmes need to be made transparent. Teaching modules may be enriched considerably by hands-on exposure to actual vaccine consultations. Factual knowledge and technical skills are just as important as personal experience and understanding of the need to vaccinate. Listening skills can be taught alongside practical immunization skills in the context of objective structured clinical examination stations or in real-life settings with actual patients. Immunization training courses should be obligatory for all medical curricula.

Experts in risk communication science could help HCPs to better understand patients' conceptual models and interpret these concerns to improve the quality of vaccine-related communication. Risk communication experts may be involved in vaccine consultation clinics as well in HCP training. This approach will aim at helping HCPs to receive and then tailor messages based on a clear assessment of common perceptions, biases, abilities and interests [3]. Information can be collected by following a three-step process:

- (a) Non-structured interviews with individuals representing the recipients of health communication in order to actively solicit their input.
- (b) Subsequent surveys based on interview results could quantify the prevalence of certain beliefs.
- (c) Risk communication messages could be developed based, in part, on the results of the interviews and questionnaires and then tested, possibly with focus groups.

With assistance from risk communication scientists the results of such studies may be used to elaborate risk communication material that is targeted to the patients' expectations. Some context will require short, simple messages that explain the risks and benefits of vaccines in non-technical language; other context will require as much scientific information as is available [20].

It must be recognized however, that even with the best communication skills, doctors will need further help. Without substantially increasing their workload, HCPs could communicate more effectively if they included external partners, such as patient organizations and public health agencies.

Conclusions

Maintaining trust in vaccines and vaccination is vital to the continuing success of this highly important public health measure. The patient voice will take an increasingly important role in vaccine communication both in the social media sphere and the consulting room. There is a general paradigm shift towards patient empowerment and self-governance. This will continue the gradual departure from paternalistic views such as 'the doctor knows best' and 'the HCP is only seen when things need to get fixed' towards a mutual and sustainable partnership in health. Bringing the HCP and the patient together in mutual partnership is the way forward. Any such initiatives should draw on pertinent communication and risk research using modern methods of data collection and collation. Individualistic attitudes and personal decision making in health are now ingrained in the public consciousness. It will be crucial to recognize and embrace the concept of personalized medicine, also in the context of vaccine prevention. Patient empowerment should not be considered a threat but rather as an opportunity to listen and understand each other's attitudes. An increased awareness of the patient viewpoint should inspire collaborative research and, above all, help to advocate for a positive attitude to vaccines and vaccination. This process will place additional responsibility on well-informed vaccine recipients and parents, who take on responsibilities regarding their own health and safety of their children. Evening courses will be offered at major health centres to prepare future parents for immunization decisions. The topic of vaccines and vaccination—including vaccine benefit–risk communication—will be embedded in a general training regarding the health and safety of infants and children. To achieve these goals, HCP reimbursement schedules will need to be reformed to allow greater emphasis on preventive measures and health consultation.

Rather than talking *at* the patient and giving orders, the physician will talk *with* the patient, taking the role of a preventive

health consultant. Medical school and residency training curricula should be adjusted to train HCPs in key competencies in this area. Such courses will teach students the practical skills of vaccination techniques along with the communication skills necessary to address this complex subject while recognizing the value of being vaccinated themselves. The training should be led by competent, certified vaccinologists, who have completed structured interdisciplinary training programmes involving infectious diseases, communication and social science, epidemiology and vaccine safety. Critical input from other scientific disciplines, for example cognitive and decision sciences, should also be mobilized.

Technology will continue to have a major impact on the dissemination of vaccines and vaccine safety information. In the future, vaccines may be tracked and geo-mapped, then monitored and verified before administration based on international bar codes. Patients should always be encouraged to report any adverse events—as well as the absence of adverse events—in real-time using smart phones and tablet devices. Direct safety reporting would provide immediate user-feedback to healthcare providers and regulatory agencies, including both uneventful vaccination events and subjective reports of adverse events. This would give patients the reassurance that they are actively invited to report and to be listened to, while providing information on the patient's subjective experience to HCPs and immunisation programmes. In the age of big data, this will add granularity to the vaccine safety data that are already gathered in large linked database systems (as supported by Kaiser Permanente and other health maintenance organizations, the Vaccine Adverse Event Reporting System and European Pharmacovigilance databases). Health authorities and HCPs will follow up with questions. Ideally, public health and regulatory authorities should also be providing online consultation services and 'open to public' days for school classes and interested patient groups to visit and be informed about the important work that is done in the monitoring of vaccine safety and effectiveness. Information provided by the HCP could then be verified online and discussed in blogs moderated by specific pro-vaccine patient and parent organizations. Such parent organizations may be directed at specific diseases or risk groups, such as pregnant mothers, age- or chronic disease-related risk groups. The increased visibility of such partnerships would encourage the formation of other proactive relationships and shift the emphasis away from negative messaging. The increasing rapport between non-governmental organizations and the public, bridging cultural and religious boundaries, will be critical in helping to establish vaccination campaigns, informed by localized knowledge on patient behaviour and attitudes.

Future research to explore the differences in benefit risk perception of different patient populations will be essential, and the building of comprehensive frameworks for assessing different age groups, as well as cultural and religious minorities will become important tools for effective implementation of vaccination programmes. Alongside this, harmonized evidenced-based guidelines and vaccination schedules for children and adults will be formulated, providing consistency to support HCPs in their messaging. These actions will not happen unless there is a concerted advocacy effort by patient groups in collaboration with healthcare professionals.

It is hoped that the political and public health climate will continue to move the important topic of vaccination up the agenda. Collaborative research networks will continue to pursue opportunities on a global scale, although it must be recognized that different strategies and tactics will be required. Large international organizations and public–private partnerships with their knowledge, experience and infrastructure are in a unique position to encourage mutual dialogue, but small local organizations focused

on communities and their leaders will become increasingly important. These opportunities must not be wasted and in the near future we will see patient groups, healthcare professionals and researchers joining together in coalition with policy makers to seize these opportunities and bring about change.

Key issues

- Vaccines target individuals of all age groups, who are mostly healthy and rarely see the need to self-organize into patient organizations unless there is a safety concern. The patient voice is therefore fragmented and complex.
- Vaccine communication should be a two-way process. Technology may help to track immunizations and vaccine safety signals in real-time, allowing patients (recipients and/or parents) to actively participate in the monitoring of vaccine safety and effectiveness.
- It is fundamental to provide proactive, personalized vaccine communication addressing the benefits and risks of vaccines in ways that are specific to, and appropriate for, each recipient or parent. Communication should include children and adolescents whenever possible.
- Patients should be encouraged to present, in their own voice, any reasons for vaccine hesitancy including concerns about the immune system, vaccine safety, risk balance, uncertain efficacy, religious and cultural norms, alternative concepts of disease, and concepts of individual responsibility and power relations.
- Healthcare professionals should be made aware that experts and non-experts perceive risk differently. While experts tend to focus on rationalizations of expected harm, public perceptions may be shaped by different factors including a perceived benevolence of nature, a sense of security when situations look familiar, and concerns for the vulnerable.
- Understanding the role of values and beliefs is essential. Awareness of different communities and cultural groups will be key to sustainable immunization programmes and disease eradication. This may include the identification of supportive neutral third parties such as political or religious leaders who are respected and may act as immunization advocates.
- Measures to improve trust in health authorities include transparent communication of risks, religious and cultural aspects, and up-to-date information. Feedback loops and interactive tools should be included, helping to restore public confidence.
- Effective training of physicians is crucial; if a physician is unfamiliar with or uncertain about vaccinations, communication will probably be avoided or inaccurate, generating mistrust. Therefore, obligatory vaccinology and vaccine safety courses should be introduced into medical school and residency training curricula.
- Communication and vaccine advocacy must be encouraged by patient groups acting together with HCPs and policy makers to bring about change.

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DH and BR developed the initial concept and the first draft of the manuscript. BR coordinated and supervised the writing process. All authors contributed to revising and developing the content and provided substantial input to the manuscript. BR and FB finalized the manuscript for publication. All authors approved the final version of the manuscript. There are no additional contributors to acknowledge. The work was not previously presented but was submitted in abstract format to the Society for Risk Analysis Annual Meeting, San Diego, CA, USA, 11–15 December 2016 and accepted for oral presentation.

Transparency Declaration

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