

# Beyond the Knowledge Gap Paradigm: The Role of Psychological Empowerment in Parents' Vaccination Decision

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*To S., L. and V.*

## **Summary**

Even though the efficacy and safety of immunization have been widely proven (Plotkin, 2014), an increasing number of parents have refused to vaccinate their children against serious infectious diseases in the past twenty years (Dubé, Gagnon, Nickels, Jeram, & Schuster, 2014). A recent shift in the study of vaccination decision-making has seen scholars moving beyond the idea that mere lack of knowledge could explain why parents decide to opt out of the recommended schedule, showing that making a vaccination decision is a complex cognitive and emotional process where several factors play a role. Variables such as risk perception, anticipated regret or prosocial attitude can potentially contribute to choosing or not choosing a given vaccination (Yaqub, Castle-Clarke, Sevdalis, & Chataway, 2014).

The aim of this dissertation, which is based on the Health Empowerment Model (Schulz & Nakamoto, 2013), is to explore and assess the role of vaccination knowledge (as a dimension of vaccination literacy) in parental vaccination decision-making, while studying, at the same time, the implications of parents' psychological empowerment on the decision about immunizing their child, with a special focus on the measles-mumps-rubella (MMR) vaccination. Six unique studies that employed both qualitative (individual interviews and focus groups) and quantitative (content analysis, survey and experiment) methods are presented, which aim to assess the influence of vaccination literacy and psychological empowerment on vaccination-related outcomes such as intention, while providing a valid and reliable measurement tool for the empowerment construct as well as a context-specific conceptualization.

A content analysis (Chapter II) focusing on the arguments cited by users posting online about vaccination shows that a distinction can be made between an anti-vaccination group, a general pro-vaccination group (using diverse arguments supporting vaccination) and a safety-focused pro-vaccination group. The anti-vaccination group appears to be more active than the others and to also use multiple sources (mainly its own experience and media).

The findings of an interview study (Chapter III) reveal that parents tend to misinterpret current vaccination recommendations and experience negative outcomes of their low self-perceived competence. The study also shows that parents think that their MMR vaccination decision can have an impact on different levels and that they have a preference for shared-decision making in relation to their child's healthcare provider.

A second qualitative study employing focus group interviews (Chapter IV) shows that parents are concerned with their legal responsibility and issues of freedom with regards to the MMR vaccination decision. A key finding is that parents' relationship with the pediatrician in terms of trust is crucial to their self-perceived competence, suggesting their preference for a model of autonomy that does not exclude a shared decision-making approach with the child's healthcare provider. Finally, a distinction emerges between information seekers, avoiders, and passive recipients.

A scale is developed and its psychometric properties are evaluated (Chapter V) to provide a valid and reliable tool to measure psychological empowerment in the vaccination decision. The final tool captures parents' perceived influence of one's personal and family experience regarding vaccination, their desire not to ask other parents about their experience with vaccinations and their lack of interest in the vaccination opinion of other parents. These elements can be seen as context-specific extensions of the empowerment dimension of self-determination.

The findings of an experimental study (Chapter VI) demonstrate that providing accurate information on the vaccination through a smartphone app employing gamification can positively and significantly increase parents' knowledge and empowerment. Furthermore, providing information in a gamified way also led to a higher intention to vaccinate and higher parental confidence in the decision.

Finally, a mixed method study to evaluate the experiment described above (Chapter VII), suggests that parents have a preference for information and opinions, compared to solely being empowered and pushed to look for information. The results recommend that empowering efforts be always accompanied by proper and exhaustive information.

## *Summary*

On the basis of these findings, this dissertation contributes to understanding parents' empowerment needs in the vaccination decision, providing new insights to current research that seeks to study the vaccination decision as a complex process. The results of the studies can significantly inform ways to improve not only communication between health professionals and parents on the vaccination topic, but also future public health strategies and policies ultimately aimed at increasing vaccination coverage.

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# **Chapter I**

## Introduction

*Marta Fadda*

## **1.1 The phenomenon of vaccine hesitancy**

To effectively protect individuals and communities from serious infectious diseases, the success of mass childhood immunization depends on high levels of vaccination uptake (Hobson-West, 2003). To eradicate measles, for example, the World Health Organization recommends that 95% of individuals be immunized with two doses of a measles-containing vaccine, such as the measles-mumps-rubella vaccination, also known as MMR (World Health Organization, 2017).

Despite official recommendations, however, the number of parents refusing part of or all scheduled immunizations has been on the rise in many countries for the past twenty years, with some scholars referring to a “vaccine crisis of public confidence” (Black & Rappuoli, 2010; Cooper, Larson, & Katz, 2008). Most countries are below the recommended threshold for eliminating serious diseases, such as tetanus, measles or rubella. For example, DTaP vaccination coverage in the US was at 84.2% in 2014, despite the Healthy People 2020 goal of 90% coverage (Centers for Disease Control and Prevention, 2017). Similarly, Switzerland is still far from reaching the recommended threshold for eradicating measles. To date, only 87% of Swiss children aged two have received two doses of the MMR vaccination (Federal Office of Public Health, 2015).

Vaccination refusal represents a serious threat to modern public health systems, since the rate of unvaccinated children has been linked to an increased incidence of vaccine-preventable diseases and outbreaks of diseases (Williams, 2014). For example, Swiss suboptimal MMR coverage resulted in a number of large measles outbreaks in the last two decades (Richard & Masserey Spicher, 2007, 2009; Federal Office of Public Health, 2017). In this sense, suboptimal vaccination coverage represents a risk not only at the individual, but also at community level (Siddiqui, Salmon, & Omer, 2013).

Vaccine hesitancy has existed since the introduction of vaccines (Gowda & Dempsey, 2013; Siddiqui et al., 2013), but literature has generally been unclear on what exactly this phenomenon encompasses, with a dominating view separating those that accept from those that delay or refuse a given vaccine (Dubé et al., 2013). More recently, as evidence on vaccination decision-making has grown, scholars have made efforts to provide a more nuanced definition of vaccine hesitancy. Recent studies have shown that

the outcomes of people's vaccination decision can be located on a larger spectrum that ranges from active demand to complete rejection (Benin, Wisler-Scher, Colson, Shapiro, & Holmboe, 2006; Dubé et al., 2013; Larson, 2013; Opel, Mangione-Smith, et al., 2011; Williams, 2014). For instance, Gust and colleagues have distinguished five different types of parental attitudes towards vaccination: the "immunization advocates," the "go alongs to get alongs," the "health advocates," the "fence-sitters" and the "worrieds." (Gust, Brown, et al., 2005; Gust, Kennedy, et al., 2005). In a similar fashion, Keane and colleagues have identified four parent types: the "vaccine believers", the "cautious" parents, the "relaxed" parents and the "unconvinced" parents (Keane et al., 2005). Finally, Benin and colleagues have proposed a categorization into four categories: the "accepters", the "vaccine-hesitant", the "late vaccinators" and the "rejecters" (Benin et al., 2006). Thus, vaccine-hesitant individuals are defined as a heterogeneous group located in the middle of this continuum who may refuse some vaccines, but agree to others, as well as delay vaccines or accept vaccines according to the recommended schedule, but not being convinced of their decision (Dubé et al., 2013).

As different studies have pointed out (Freed, Clark, Butchart, Singer, & Davis, 2010), the fact that vaccine hesitancy is not directly related to vaccine uptake (as individuals may report to have significant concerns about vaccination but still state their intention to undergo immunization) makes successful vaccination promotion an even more challenging task. Furthermore, research has shown that vaccine hesitancy can vary depending on the vaccine involved (one can be hesitant regarding the flu vaccine, but accept all other vaccines with confidence), with newer vaccines usually causing more hesitancy (Dubé et al., 2013). To build effective immunization promotion campaigns, research has paid attention to the processes involved in individuals' vaccination decision-making and, most importantly, to the drivers that could possibly affect one's immunization decision. The following paragraph will seek to summarize the literature on the factors affecting parental vaccine hesitancy

## **1.2 Factors affecting vaccine hesitancy**

Research on vaccine acceptance has shown that individuals' decision-making regarding vaccination is extremely complex and may involve emotional, cultural, social, spiritual or political factors as much as cognitive ones (Dubé et al., 2015). In particular, studies have demonstrated that parents' past experiences with health services, family histories, their feelings of control, or conversations with friends can all influence the decision-making process regarding the vaccination of their child just as much as their perception of the risks posed by the disease (Dubé et al., 2013). Following a number of reviews (Brown et al., 2010; Roberts, Dixon-Woods, Fitzpatrick, Abrams, & Jones, 2002; Serpell & Green, 2006; Tauil, Sato, & Waldman, 2016; Yaqub et al., 2014) and meta-analyses (Brewer et al., 2007; Tabacchi et al., 2016), scholars have sought to categorize the different levels of factors affecting parental vaccine hesitancy within a number of frameworks that generally distinguish between parent-specific (or internal), vaccine-specific, and external factors (Gowda & Dempsey, 2013; Burton-Jeangros, Golay & Sudre, 2005; Streefland, Chowdhury, & Ramos-Jimenez, 1999; Benin et al., 2006; Gust, Brown, et al., 2005; Gust, Kennedy, et al., 2005; Brown et al., 2011).

### *1.2.1 Parent-specific (or internal) factors*

Research has shown that parental characteristics such as socio-economic status, race/ethnicity, education level, knowledge about vaccines and past experiences with vaccinations and diseases can potentially have an influence on their perception of the risks of a given disease and of vaccine adverse events (Gowda & Dempsey, 2013).

Regarding the role of parents' socio-economic status, evidence appears to be mixed. While a number of studies found that parents of lower-income brackets had greater levels of concern about vaccination (Brown et al., 2010; Gust et al., 2003; Kennedy, Brown, & Gust, 2005; Opel, Taylor, et al., 2011; Shui, Weintraub, & Gust, 2006), others detected an opposite trend (Opel, Taylor, et al., 2011), with wealthier parents being more likely to vaccinate.

Some studies have also shown that race/ethnicity is associated with different types and levels of concerns regarding vaccination, with Black and Hispanic participants being more likely to have greater concerns (Prislin, Dyer, Blakely, & Johnson, 1998; Shui et al., 2006) or be unvaccinated (Smith et al., 2011). This is, however, contradicted by the finding that Black and minority ethnicity (Brown et al., 2011) or being part of Hispanic and non-Hispanic Black families (Kim, Frimpong, Rivers, & Kronenfeld, 2007) predicted uptake.

A large number of studies found that education level is significantly and negatively associated with the intent to immunize or immunization status, indicating that higher-educated parents are more likely to opt out of vaccination (Walsh, Thomas, Mason, & Evans, 2015; Humiston, Lerner, Hepworth, Blythe, & Goepp, 2005; Smith et al., 2011; Kim et al., 2007; Pearce et al., 2008; Kriwy 2012). This is confirmed by Veldwijk and colleagues (2015), who found that only lower educated parents were willing to vaccinate if a national immunization program vaccine was offered on the free market (Veldwijk et al., 2015). In other studies, however, the opposite trend was detected (Gust et al., 2003; Gust, Brown, et al., 2005; Gust, Kennedy, et al., 2005; Opel, Taylor, et al., 2011; Prislin et al., 1998; Shui et al., 2006). For instance, delayed or non-immunization was associated with maternal illiteracy (Rahman, Islam, & Mahalanabis, 1995) and maternal education of high school or lower at the time of the child's birth (Miller et al., 1994). A study conducted in Africa found that education was strongly and positively associated with vaccine uptake (Jung et al., 2015).

A number of studies found an association between poor objective knowledge of the vaccination and delayed or refused vaccination status (Borràs et al., 2009; Humiston et al., 2005; Rahman et al., 1995; Miller, Hoffman, Barón, Marine, & Melinkovich, 1994). Freeman and Freed (1999) found that intention to vaccinate was predicted also by poor subjective knowledge about the vaccine (Freeman & Freed, 1999). In terms of health literacy, intention to vaccinate with a vaccine offered on the free market rather than as part of a national program was higher among health literate parents (Veldwijk et al., 2015).

Regarding experience, Freeman & Freed found that parents who vaccinated or intended to vaccinate reported past experience with a disease among family members or friends more frequently compared to non-vaccinators (Freeman & Freed, 1999).

Regarding past behavior, studies found that parents who had previously vaccinated their children had higher intentions to vaccinate (Abhyankar, O'Connor, & Lawton, 2008; Pareek & Pattison, 2000; Brown et al., 2011; Flynn & Ogden, 2004; Le Menach et al., 2014).

Furthermore, when considering the risks and benefits of vaccination, parents are subject to a number of biases, such as “compression” bias which leads to an over-estimation of the frequency of unlikely risks (such as serious adverse events) and an under-estimation of frequent risks, such as those occurring when a disease is contracted (Ball, Evans, & Bostrom, 1998; Siddiqui et al., 2013). “Ambiguity aversion” influences people to favor known risks, such as those from diseases, rather than unknown risks that are less frequent, such as the possibility for adverse reactions to a vaccine. Furthermore, there is a preference for “natural risks” (disease) over “man-made risks” (vaccination), as well as a preference for “errors of omission” (risks of not vaccinating) over “errors of commission” (risks of vaccination). Finally, reports of vaccine-adverse events are often distorted and amplified by media and the internet, which leads parents to over-estimate the frequency of events that are simply more “accessible” than others (Siddiqui et al., 2013).

### *1.2.2 Vaccine-specific factors*

Concerns about the safety of vaccines, such as the fear of the short- and long-term side-effects or discomfort associated with vaccinations, the number of injections that the child receives and their timing, perceptions about vaccine efficacy (vaccine-induced immunity vs. immunity obtained through the disease), the importance attached to a vaccine and changes to the official vaccination schedule can all affect parents’ perceptions of the risks and benefits of a given vaccination.

Although the association between the MMR vaccination and autism has been scientifically discarded (Madsen et al., 2002), research has found that parents who delayed and refused vaccines were significantly less likely to believe that vaccines are safe (Allison et al., 2010; Betsch & Sachse, 2012; Thorpe, Zimmerman, Steinhart, Lewis, & Michaels, 2012; Gust et al., 2003; Gust, Brown, et al., 2005; Gust, Kennedy, et al., 2005; Smith et al., 2011; Gust, Darling, Kennedy, & Schwartz, 2008; Meszaros et al., 1996; Pareek &

Pattison, 2000) and more likely to believe that vaccination is unhealthy (Flynn & Ogden, 2004) or may cause autism (Bardenheier, Yusuf, Rosenthal, et al., 2004; Bardenheier, Yusuf, Schwartz, et al., 2004; Benin et al., 2006; Freed, Clark, Hibbs, & Santoli, 2004; Kennedy, Basket, & Sheedy, 2011). Fear of autism is still a frequently reported vaccine safety concern today among parents in different settings (Poland & Spier, 2010). Strong positive correlations with intention were also found for the perceived benefits of the vaccination (Harmsen et al., 2012). In a similar fashion, Bennett and Smith (1992) found that those who did not vaccinate their children had significantly more concerns over their child experiencing long-term health problems as a result of the vaccination than respondents who fully or partially vaccinated their children (Bennett & Smith, 1992). A role in predicting vaccination status is also played by the importance attached to the risk of adverse reactions (Gellatly, McVittieb, & Tiliopoulos, 2005), as well as the number of reported vaccine concerns (Wheeler & Bутtenheim, 2013). Regarding the disease, the perceived risk of a disease by parents and their anxiety about the disease predicted intention in one study (Abhyankar et al., 2008). In other studies, the perceived severity of the illness if the child was not immunized predicted either intention or vaccination status. Compared to pro-vaccination parents, non-vaccinators believed the disease was less dangerous (Meszaros et al., 1996; Kriwy 2012; Bennett & Smith, 1992; Abhyankar et al., 2008). Regarding the disease's susceptibility, anti-vaccination parents reported a lower perceived probability of contracting the target illness (Meszaros et al., 1996; Allison et al., 2010; Bennett & Smith, 1992; Smith et al., 2011; Bennett & Smith, 1992).

Strong positive correlations with intention and vaccination status were also found for the perceived effectiveness of the vaccination (Bennett & Smith, 1992; Meszaros et al., 1996, Pareek & Pattison, 2000), with parents reporting a preference for natural immunity vs. vaccine-induced immunity (Kennedy & Gust, 2008; Prislin et al., 1998; Salmon et al., 2009).

Several studies found that non-vaccinators perceived the vaccination and the eradication of a disease to be significantly less important than vaccinators (Bennett & Smith, 1992; Lavail & Kennedy, 2012; Lin et al., 2006; Gellatly et al., 2005; Humiston et al., 2005) and that they were less likely to agree that vaccinating was a good idea (Thorpe

et al., 2012) or that it was necessary to protect the health of children (Smith et al., 2011; Wheeler & Buttenheim, 2013).

### *1.2.3 External factors*

A third typology of factors that contribute to vaccine hesitancy are external factors such as parents' relationship with the healthcare provider, school immunization requirements and policies, social norms, and media (Gowda & Dempsey, 2013).

The child's health care provider is constantly cited by parents as the most important source for vaccine-related information, and the provider's recommendation to vaccinate is one of the most important drivers of vaccine uptake (Gust et al., 2008; Luthy, Beckstrand, & Peterson, 2009; Smith, Kennedy, Wooten, Gust, & Pickering, 2006; Williams, 2014). Furthermore, several studies revealed that the strength of the provider's recommendation on immunization could positively influence parents' confidence in their vaccination decision and ultimately their intention to vaccinate (Gust et al., 2003; Smith et al., 2006). Parents' trust in the provider also appears to be important, with studies showing that the more parents trust their child's provider, the more confidence they will have in the vaccination (Gust et al., 2003).

Public health and vaccine policies also seem to have an impact on parental vaccination decision. School requirements may help increase vaccination coverage, as some studies have demonstrated (Dempsey & Schaffer, 2010; Gowda & Dempsey, 2012; Olshen Kharbanda, Stockwell, Colgrove, Natarajan, & Rickert, 2010). However, there is also evidence that making vaccination compulsory may generate more resistance from the parents' side (Haverkate et al., 2012; Lantos et al., 2010).

The perception that vaccination is a social norm is another potential driver of the vaccination decision. This belief predicted both intention (Harmsen et al., 2012; Abhyankar et al., 2008) and receipt (Allison et al., 2010). Family member's belief that the child should be vaccinated also predicted vaccination status (Lin et al., 2006), while positive social attitudes, namely the desire to protect other children by vaccinating one's own child, predicted uptake (Brown et al., 2011; Lavail & Kennedy, 2012) and intention (Wallace, Leask, & Trevena, 2006).



Since its introduction vaccination has been a target for misinformation and the subject of many different controversies and vaccination scares (Dubé et al., 2013; Spier, 2001). In this context, the role of media and communication has been critical in fueling parents' concerns, with the anti-vaccination movement amplifying these scares and helping them to cross borders (such as the well-known association between the MMR vaccination and autism that was first publicized in the United Kingdom, but then quickly spread worldwide) through traditional media first, and the Internet today. The Internet represents a tremendous opportunity for the diffusion of vaccination campaigns (Wilson, Atkinson, & Deeks, 2014), but also a fertile ground for anti-vaccination advocates (Betsch, 2011; Betsch et al., 2012; Zimmerman et al., 2005). In addition, Web 2.0 applications allow users to share their personal experiences with vaccination and, considered the power of narrative to have far greater potential to negatively influence parents' vaccination attitudes (Betsch, Renkewitz, & Haase, 2013; Brown & Sevdalis, 2011; Haase & Betsch, 2012) than, for instance, statistical information on the incidence of a given disease.

Finally, historical, political and socio-cultural changes are also responsible for fueling vaccine hesitancy (Larson, Brocard Paterson, & Erondy, 2012; Larson, Cooper, Eskola, Katz, & Ratzan, 2011). These include a widespread distrust in pharmaceutical companies that produce vaccines and the government that widely purchases and promotes vaccines, as well as distrust in science and the medical community (Cooper et al., 2008; Poland, Jacobson, & Ovsyannikova, 2009). This phenomenon has resulted in a growing public interest in “natural” products and, consequently, in alternative types of medications and non-medical ways to prevent illness.

### **1.3 Vaccination literacy and psychological empowerment as drivers of the vaccination decision**

While support for vaccines from pediatricians and other health professionals has shown to be crucial for generating or reinforcing parents' trust in immunization (Gust et al., 2008; Smith et al., 2006), it should be recognized that the healthcare model has significantly changed over the years. Today, many parents no longer want to be told what to do for the health of their children by their pediatrician, but rather prefer to make decisions themselves (Cooper et al., 2008). In this relatively new context, the Internet plays a special role,

reinforcing feelings of control and a perception of being informed on the subject of vaccination (Samoocha, Bruinvels, Elbers, Anema, & van der Beek, 2010; Wilson & Keelan, 2013)

Recently, Schulz and Nakamoto (2013) proposed a theoretical model that, if applied to the subject of vaccination, aimed to explain parents' vaccination decision as a function of vaccination literacy, on the one hand, and psychological empowerment, on the other (Schulz & Nakamoto, 2013). The model, called the Health Empowerment Model (HEM), recognizes the importance of the quality of parents' information regarding a given vaccination as a key variable affecting parents' vaccination decision and includes, at the same time, the construct of psychological empowerment (e.g. parents' perceived competence and self-determination) as an equally important and independent variable (Schulz & Nakamoto, 2013).

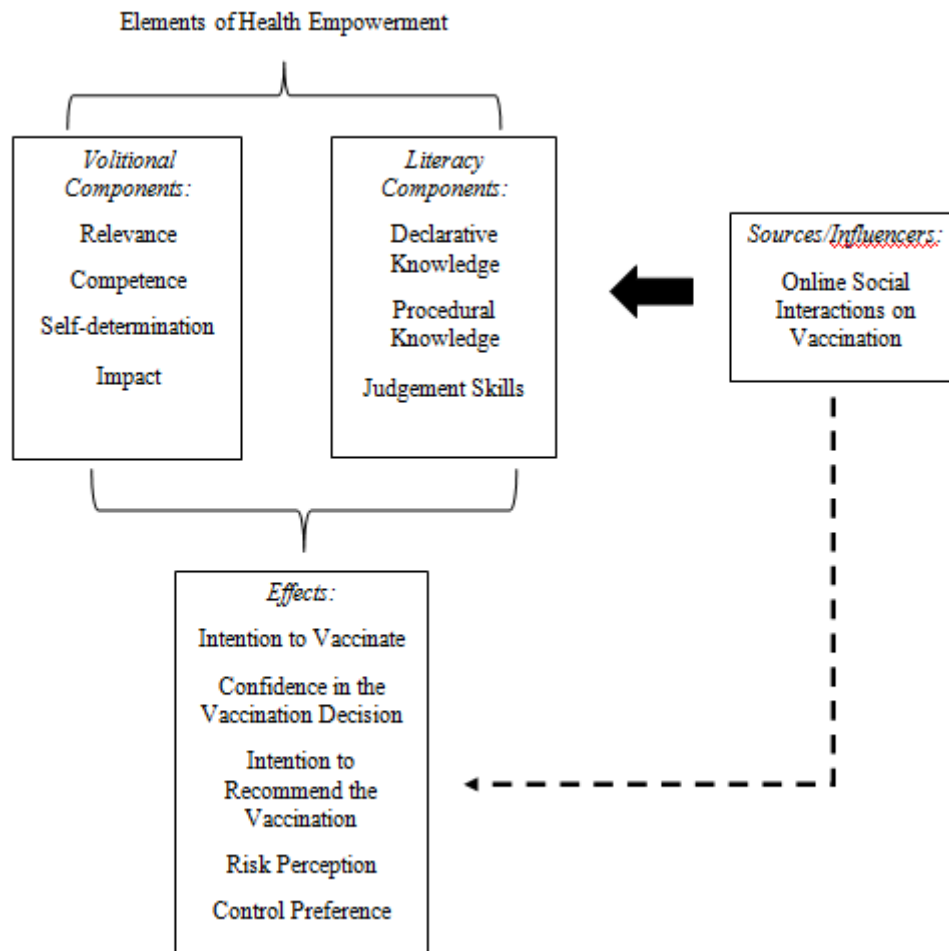
Vaccination literacy can be seen as the context-specific counterpart of health literacy, defined as "the capacity to acquire, understand and use information in ways which promote and maintain good health" (Nutbeam, 2009). In order to stress its multidimensionality, Schulz & Nakamoto (2013) break down this concept, defining it as a set of four sub-dimensions: (a) functional literacy, (b) declarative knowledge, (c) procedural knowledge, and (d) judgment skills. Vaccination literacy can be conceptualized as a multi-dimensional construct comprising parents' knowledge about vaccinations and their ability to find, judge and use vaccination-related information (Fadda, Depping & Schulz, 2015). Vaccination knowledge can be further defined as either declarative or procedural. Declarative knowledge includes, for instance, knowledge about infectious diseases, the availability of vaccines, or the likelihood and severity of their side effects. Procedural knowledge entails notions such as knowing how and when to get vaccinated against vaccine-preventable diseases (Fadda, Depping, et al., 2015).

Psychological empowerment, i.e. empowerment at individual level (rather than at collective or organizational levels), is an intrinsic motivational construct of the individual manifested in four cognitions (Spreitzer, 1996): (a) meaningfulness (how far what an individual does is perceived as being important), (b) competence (how far an individual perceives himself/herself to be competent to carry out an action), (c) impact (how far an

individual perceives himself/herself to be making a difference through a given action) and (d) self-determination (how far an individual perceives himself/herself to be autonomous). Adjusted to the context of parental vaccination decision-making, the four sub-dimensions of psychological empowerment can be operationalized as follows: (a) meaningfulness, or the degree to which an individual thinks that making a vaccination decision regarding his or her child is important; (b) competence, or the degree to which an individual feels able to make a vaccination decision; (c) impact, or the degree to which an individual feels that making a vaccination decision can generate certain outcomes; (d) self-determination, or the degree to which individuals think that their vaccination decision is determined by themselves (Fadda, Depping, et al., 2015).

According to the HEM (Schulz & Nakamoto, 2013), online social interaction about vaccinations can directly affect individuals' vaccination literacy (by means of providing more or less correct information on the immunization) and psychological empowerment (by means of increasing a sense of self-determination and self-efficacy). Both literacy and volitional components are considered to have a direct effect on key vaccination-related variables, such as intention to vaccinate, confidence in the vaccination decision, intention to recommend the vaccination, risk perception and control preference (Schulz & Nakamoto, 2013). Furthermore, online social interaction is presented as having an indirect effect on such key outcomes (Figure 1). The model seeks to overcome the knowledge gap paradigm, which posits that individuals will opt for the vaccination if provided with the right and appropriate information, recognizing that good information alone is not enough if not coupled with high psychological empowerment (Connolly & Reb, 2012; Schulz & Nakamoto, 2013). It also suggests the potential danger of vaccination misinformation when this is coupled with high parental empowerment (Diviani, Camerini, Reinholz, Galfetti, & Schulz, 2012; Schulz & Nakamoto, 2013). Indeed, most past vaccination interventions were mainly based on a knowledge-gap approach, which assumed that vaccine-hesitant individuals would change their mind if they were given the proper information (Dubè et al., 2015). The HEM, which has been applied to a number of contexts, including eHealth interventions (Camerini & Schulz, 2012) and studies on chronic patients' self-management (Camerini, Schulz, & Nakamoto, 2012), medication

adherence (Náfrádi, Galimberti, Nakamoto, & Schulz, 2016) and low back-pain (Camerini, Schulz, Deveugele, Derese, & Maeseneer, 2015; Riva, Camerini, Allam, & Schulz, 2014; Trentini, Malgaroli, Camerini, Serio, & Schulz, 2015), contributes to the current understanding of vaccination decision-making by adding the psychological empowerment component in order to explain what knowledge alone cannot. Ideally, people will possess the adequate knowledge and skills to manage their children's care, but also the commitment and motivation to make autonomous and impactful decisions (Schulz & Nakamoto, 2013).



**Figure 1.** Health Empowerment and its effects (Schulz & Nakamoto, 2012)

#### 1.4 Main objectives and organization of the study

The following chapters (II-VII) represent six different studies that were carried out either in Italy or Switzerland between 2013 and 2017. They correspond to six unique articles either published or under review in a peer-reviewed scientific journal. Some of these studies are the result of international collaborations with renowned institutions, such as the University of Milan, the University of Erfurt, and Yale University.

While every chapter has specific aims and research questions, all articles share a common, broader research question: how can our understanding of the vaccination

decision benefit from studying the concept of psychological empowerment? More specifically, this dissertation will have a special focus on the MMR vaccination. This vaccination, in fact, presents different characteristics that distinguish it from other childhood vaccinations. First, it was at the center of the well-known MMR scare triggered by a Lancet article in 1998 (Maisonneuve & Floret, 2012). Second, the MMR vaccination's timeliness is associated with decreased outbreak risk (Dannetun, Tegnell, Hermansson, Törner, & Giesecke, 2004). Finally, the MMR vaccine is often perceived by parents as more dangerous compared to other vaccines, since it is made of attenuated viruses and thus the closest thing to an infection (Centers for Diseases Control and Prevention, 2015b).

In light of the strong online presence of the anti-vaccination movement, Chapter II describes the development and results of a quantitative content analysis of online posts addressing the vaccination topic. The analysis of more than 6500 different messages reveals different patterns in terms of users' arguments and cited sources, contributing to understanding what users interested in the vaccination topic will find in three popular online forums. Based on the comparison between the two types of clusters (arguments and sources), recommendations are provided for future interventions on online platforms.

Chapter III presents a qualitative exploration of the two concepts of vaccination literacy and psychological empowerment in the MMR vaccination decision with a sample of parents residing in the Italian-speaking part of Switzerland. The transcripts of twenty individual interviews are inductively analyzed to reveal four main themes. The implications of the findings are presented for the communication between parents and their child's pediatrician.

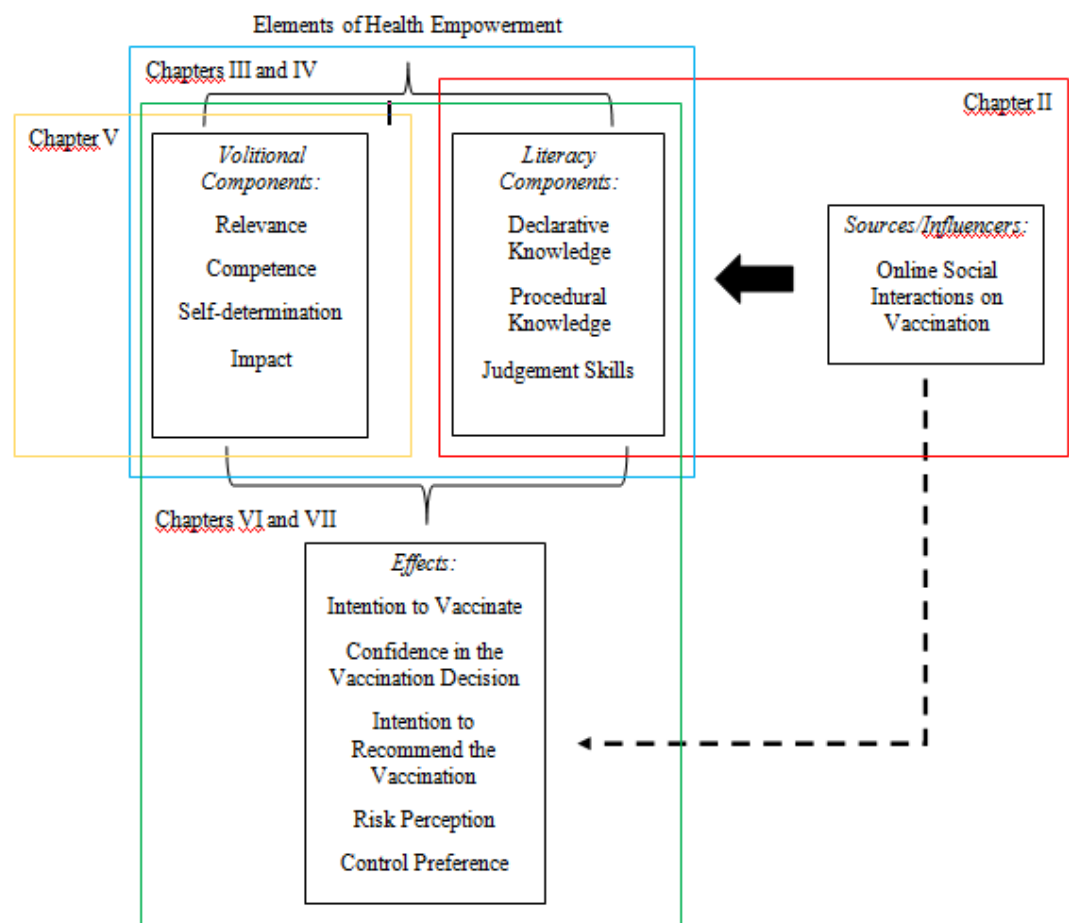
Chapter IV provides insights into the significance parents residing in a low MMR vaccination-covered area in Italy attribute to vaccination literacy and psychological empowerment regarding the MMR vaccination decision. The results of six focus group interviews highlight tensions of opinion between favorable and hesitant parents. Parents' ethical concerns on issues of freedom and legal responsibilities are discussed in terms of what they add to current conceptualizations of psychological empowerment in other health domains.

In an effort to provide a valid and reliable measurement tool for a future quantitative assessment of psychological empowerment in the vaccination decision, Chapter V describes the development of a scale to measure this construct and the evaluation of its psychometric properties. In light of the positive association between psychological empowerment and major vaccination-related outcomes, such as intention to vaccinate, the chapter calls for more research on the role of psychological empowerment in vaccination decision-making.

Chapter VI describes the development of two smartphone interventions aimed at enhancing parents' vaccination knowledge and psychological empowerment, respectively. The intervention is tested in a randomized controlled trial, where the two variables are manipulated and their effects tested on a number of vaccination-related outcomes. Special attention is devoted to the limitations of the study in order to offer suggestions on ways to improve future mobile interventions on vaccination.

Chapter VII presents an evaluation of the smartphone intervention presented in the previous chapter, using a mixed method approach. A survey is employed to collect information on parents' rating of the tool, while individual interviews are conducted to explore their experience with the application. The results contribute to explaining the RCT's quantitative results, as well as to provide recommendations for future intervention design.

Finally, Chapter VIII presents a summary of the major findings that emerged from the six studies presented in the dissertation, a discussion of the opportunities and challenges of employing the Health Empowerment Model in the vaccination context, the limitations of the present project, and possible future directions for research. Lastly, this chapter addresses the implications of the studies' findings for public health campaigns and parent-pediatric communication.



**Figure 2.** Objectives of the studies



## Chapter II

### Arguments and sources on Italian online forums on childhood vaccinations: Results of a content analysis

*Marta Fadda, Ahmad Allam, & Peter J. Schulz*

*Manuscript published*

Fadda, M., Allam, A., & Schulz, P. J. (2015). Arguments and sources on Italian online forums on childhood vaccinations: Results of a content analysis. *Vaccine*, 33, 7152–715

*Abstract*

**Background:** Despite being committed to the immunization agenda set by the WHO, Italy is currently experiencing decreasing vaccination rates and increasing incidence of vaccine-preventable diseases. Our aim is to analyze Italian online debates on pediatric immunizations through a content analytic approach in order to quantitatively evaluate and summarize users' arguments and information sources.

**Methods:** Threads were extracted from 3 Italian forums. Threads had to include the keyword Vaccin\* in the title, focus on childhood vaccination, and include at least 10 posts. They had to have been started between 2008 and June 2014. High inter-coder reliability was achieved. Exploratory analysis using k-means clustering was performed to identify users' posting patterns for arguments about vaccines and sources.

**Results:** The analysis included 6544 posts mentioning 6223 arguments about pediatric vaccinations and citing 4067 sources. The analysis of argument posting patterns included users who published a sufficient number of posts; they generated 85% of all arguments on the forum. Dominating patterns of three groups were identified: (1) an anti-vaccination group (n = 280) posted arguments against vaccinations, (2) a general pro-vaccination group (n = 222) posted substantially diverse arguments supporting vaccination and (3) a safety-focused pro-vaccination group (n = 158) mainly forwarded arguments that questioned the negative side effects of vaccination. The anti-vaccination group was shown to be more active than the others. They use multiple sources, own experience and media as their cited sources of information. Medical professionals were among the cited sources of all three groups, suggesting that vaccination-adverse professionals are gaining attention.

**Conclusions:** Knowing which information is shared online on the topic of pediatric vaccinations could shed light on why immunization rates have been decreasing and what strategies would be best suited to address parental concerns. This suggests there is a high need for developing automated approaches to detect misleading or false information on the Internet.

*Keywords*

Childhood vaccinations, Italy, content analysis, anti-vaccination movement, online forums, cluster analysis.

## **2.1 Introduction**

In March 2012, a local court in Rimini, northeast Italy, awarded the Bocca family Euros 174,000 (\$240,000) after ruling that the measles–mumps–rubella (MMR) vaccination had caused autism in their child (Zunino, 2012). Not long afterwards, in November 2014, the Court of Justice in Milan issued a sanction against the Italian Ministry of Health, deeming it responsible for a child's autistic disorder, this time at the hand of the DTaP vaccination (Il Fatto Quotidiano, 2014). These events have triggered a lively dispute between a number of lawyers and the medical community about who has the right to judge what side-effects a vaccination may have.

Not surprisingly, vaccination coverage has decreased for most pediatric vaccinations in the country in the past five years, with some vaccinations being more affected than others, such as MMR, for which coverage with two doses dropped from 90.6% to 88.3% between 2010 and 2013 (Italian Ministry of Health, 2014). Italy's current epidemiological situation is not immune to the low uptake, with the country experiencing the resurgence of a number of vaccine-preventable diseases (Filia et al., 2011). Between January and December 2014, Italy experienced the highest incidence of measles in Europe, with a total of 1676 cases (28.1 cases per million; Bella et al., 2015; European Centre for Disease Prevention and Control, 2015). Other diseases that are still significantly present include mumps, pertussis, and tetanus. As for the latter, Italy displayed the highest rate in Europe in 2012 (European Centre for Disease Prevention and Control, 2015).

Drivers and barriers of vaccination behavior have been studied extensively. These include risk perception of the disease that the immunization is aimed to prevent (Betsch & Wicker, 2012), vaccine safety concerns (Bardenheier, Yusuf, Rosenthal, et al., 2004; Bardenheier, Yusuf, Schwartz, et al., 2004; Streefland, 2001), trust in health authorities (Cooper et al., 2008; Larson, Leask, Aggett, Sevdalis, & Thomson, 2013), the healthcare provider's communicative style during vaccination recommendation (Opel et al., 2013), vaccination knowledge (Betsch & Wicker, 2012; Borràs et al., 2009; Zingg & Siegrist, 2012), beliefs about the efficacy of the vaccination (Roberts, Sandifer, Evans, Nolan-Farrell, & Davis, 1995) and religious beliefs (Simpson, Lenton, & Randall, 1995), social norms (Oraby, Thampi, & Bauch, 2014), and use of complementary and alternative

medicine (Ernst, 2002; Zuzak, Zuzak-Siegrist, Rist, Staubli, & Simoes-Wüst, 2008). In terms of socio-demographic variables, known predictors are age, education, country of origin, number of children, and marital status (Borràs et al., 2009; Luman, McCauley, Shefer, & Chu, 2003; Prislín et al., 1998). More recently, the influence of the Internet on vaccination decision-making was also acknowledged and documented (Betsch, 2011, 2013; Betsch et al., 2012; Betsch, Ulshöfer, Renkewitz, & Betsch, 2011; Haase & Betsch, 2012; Witteman & Zikmund-Fisher, 2012). In addition, the topology of vaccine-critical websites was investigated, with the differences between pro- and anti-vaccination websites and their potential effects on vaccine hesitancy in view (Ward, Peretti-Watel, Larson, Raude, & Verger, 2015). In particular, research has found that Web 2.0 applications such as blogs, discussion boards and social networks might play a special role not only for being interactive, open, and friendly non-judgmental spaces, but also and foremost for providing a type of information, which usually comes in form of narratives easy to understand (Brown & Sevdalis, 2011; Brown et al., 2010; Skea, Entwistle, Watt, & Russell, 2008). This form of information is also more powerful than statistics, which usually dominate official recommendations (Betsch et al., 2013). Furthermore, a recent study found that interactive Web 2.0 platforms are also more likely to display vaccine-critical views compared to non-interactive ones (Venkatraman, Garg, & Kumar, 2015). However, few studies have so far addressed and analyzed users' online discussions about vaccinations on 2.0 platforms. While one study looked at how information on vaccinations is shared between users (Salathé & Khandelwal, 2011), others have explored online debates about MMR (Nicholson & Leask, 2012; Skea et al., 2008) and a measles outbreak (Pereira et al., 2013), HPV discussions in a blog (Keelan, Pavri, Balakrishnan, & Wilson, 2010), public concerns about Influenza A H1N1 on twitter (Signorini, Segre, & Polgreen, 2011) and news websites (Henrich & Holmes, 2011).

While Italy has almost entirely adopted a computerized immunization registry, little attention has been paid to parents' reasons for their vaccination decision and their information-sharing behavior (Angelillo et al., 1999; Attena, Valdes Abuadili, & Marino, 2014; Ciofi Degli Atti, Rota, Bella, & Salmaso, 2004). The present study aims at analyzing Italian online debates on pediatric immunizations through a content analytic approach. To

our knowledge, this is the first study to do that. We aim at understanding what the dominating posting patterns related to arguments are, which patterns of source citations can be found, and finally how the argument and the source patterns are related.

## **2.2 Material and methods**

### *2.2.1 Data sources*

To identify the Internet discussion forums to be included in the study, a combination of the Italian terms for “vaccination” and “forum” was used in Google search engine. We selected the three forums<sup>1</sup> recurring most often in the generated results. In addition, the popularity of the three domains hosting these forums was verified using the ranking by country service provided by Alexa Internet<sup>2</sup> (subsidiary company of Amazon.com). Permission to retrieve and analyze data from the forums for research purposes was obtained from the hosts.

### *2.2.2 Data extraction*

We identified and extracted all discussion threads which included the search keyword “vaccin\*” in the title. Threads had to (i) predominantly concern childhood vaccinations, (ii) generate at least 10 posts, indicating users’ active participation and affinity with the message content (Nicholson & Leask, 2012; Pereira et al., 2013) and (iii) be started between January 2008 and June 2014. It was decided that threads published before 2008 would have prolonged the work while not adding further insights. Since research has shown that a unique set of beliefs and attitudes surround each vaccination and its related disease(s) (Larson, Leask, et al., 2013), we decided not to restrict our inquiry to a specific type of vaccination.

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<sup>1</sup> The hosts of the 3 forums were: *alfemminile.com*, *nostrofiglio.it*, and *pianeta-mamma.it*.

<sup>2</sup> <http://www.alexa.com/>.

### 2.2.3 Measures

The final codebook included both formal categories (related to the characteristics of the threads and posts, usually derived directly from the text) and content categories (related to the content of each message, the coding of which required a substantial amount of inference, training and clarification). Formal categories included: (a) forum name, (b) thread ID, (c) number of contributions in the thread, (d) post ID, (e) date of publication, (f) time of publication, (g) user's nickname, and (h) user's gender. Content categories included: (a) type of vaccination discussed (up to three), (b) main argument related to the discussed vaccination (up to three arguments per vaccination), (c) information source (used to support each argument). Arguments included statements on the efficacy of immunization in preventing the disease, vaccine safety concerns, severity of and susceptibility to the disease, and the perceived benefits of vaccination compared to the risks of being exposed to the disease (and conversely). Information sources included, for instance, own experience, family and friends, and media.

### 2.2.4 Coders, coding, and intercoder reliability

Five coders participated in the coding process. All coders were native speakers of Italian, had a background in communication sciences, and had gained substantial previous experience in content analysis. To familiarize themselves with the coding measures, each coder analyzed a number of pre-selected threads. A discussion then took place among all coders on the problems encountered during the trial coding, and, where necessary, changes were made to the codebook. Each coder was then randomly assigned to a unique set of threads to be coded without a pre-fixed order. Using Fleiss' Kappa statistic, inter-rater reliability was computed on three occasions: during coders' training, in a pilot study, and once half of the sample had been coded. For each reliability check, coders were assigned to a common thread randomly extracted from the sample. Each reliability check was followed by a discussion among all coders, where results were carefully examined and agreement established. The inter-rater reliability was found to be on average Kappa = 1 for formal and Kappa = 0.86 for content categories during the last check (see Appendix 1 for more details).

### *2.2.5 Statistical analyses*

A descriptive analysis of all collected posts was done. Subsequently, we performed an exploratory cluster analysis using k-means algorithm to group (1) users who shared the same posting pattern with respect to the arguments mentioned, and (2) users sharing a pattern in citing sources.

### *2.2.6 Argument and source clustering*

The cluster analysis established four classes of arguments: (1) safety of vaccination, including arguments about the possible side effects of a vaccination (“The MMR vaccination can cause autism” or “The worst consequence of the DTaP vaccination is redness or swelling where the shot was given”); (2) efficacy of vaccination, including arguments about the coverage and reach of the vaccination (“The Meningococcal vaccination only covers few strains” or “The baby’s immune system is not perfect and cannot deal with infections on its own”); (3) disease severity and susceptibility, including arguments about how serious a disease is and how likely it is to catch it (“Measles can be deadly” or “We all had chickenpox and are still alive”); (4) risks vs. benefits of vaccination (“The risks posed by tetanus are far greater than the possible side effects of its vaccination” or “The MMR vaccination is much more dangerous than contracting measles or rubella”). In addition, the polarity of the posted argument (for or against vaccination) was recorded. As a result, a vector with eight components (4 types of arguments X 2 polarity positions) represented each user. This allows the use of the clustering algorithm for identifying users who post similar arguments. To compensate for users’ different activity, we normalized each user’s vector dividing it by its Euclidean norm to obtain a vector with 8 components summing to 1.

The clustering of users according to the source proceeded in the same way, only that the user was represented by a vector with 11 components comprised of the normalized counts for the 11 source categories offered in the codebook: (1) own experience, referring the user’s personal account, (2) relative or friend, referring to close parental or friendship sources, (3) friend of friend/relative, referring to more distant informants, (4)



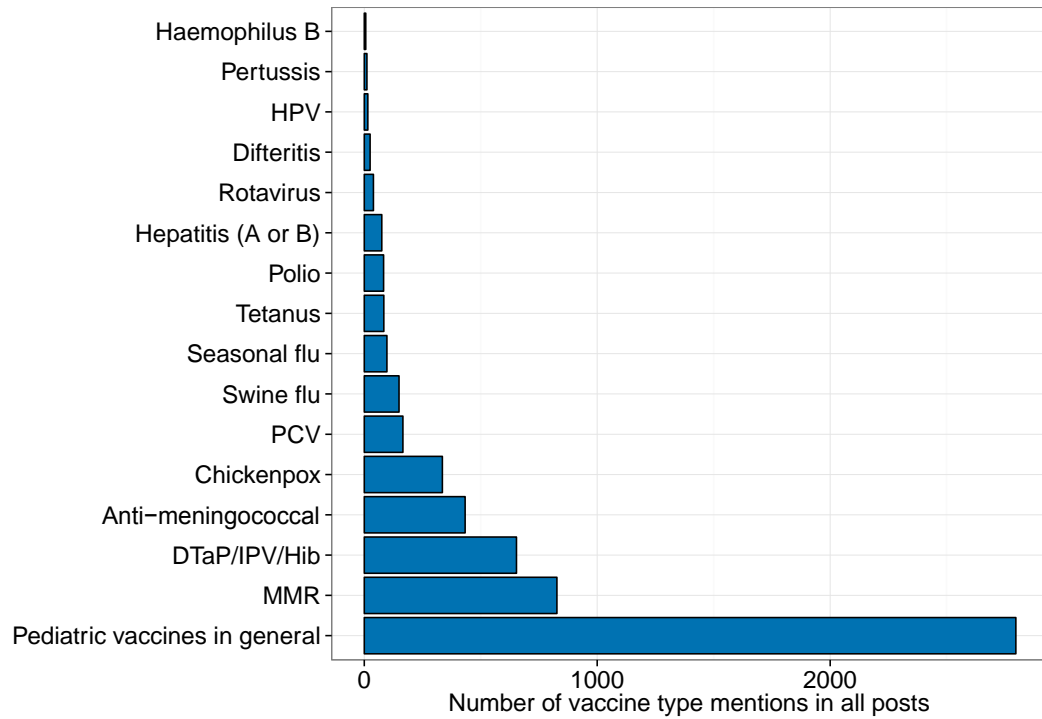
Facebook/other social network contact, (5) doctor/other medical professional, (6) anti-vaccination activist, (7) CAM professional, (8) book, (9) teacher, (10) media, and (11) rumors, referring to all instances where users reported something “they have heard” or “is being said”.

To allow for meaningful analysis, users were included if they posted at least 3 arguments in case of the first clustering and 3 sources for the second clustering. The k-means algorithm was run with multiple random starting centroids to avoid bad initialization/placement of center points in both clustering occasions. Moreover, the number of clusters was determined after running the algorithm for multiple numbers of clusters ( $k$ ) and inspecting a scree/elbow plot that reported the within cluster sum of squares with respect to the different number of clusters. In addition, we evaluated internal metrics and heuristics such as average silhouette width (Rousseeuw, 1987) for each cluster. Hence,  $k = 3$  for the first clustering and  $k = 4$  for the second were a good choice. A radar/spider plot was used to represent the resulting cluster solutions. Cluster names were given based on the dominant or standing-out features in each cluster. All statistical analyses were performed using R version 3.0.2 (R Foundation for Statistical Computing, Vienna, Austria).

## 2.3 Results and discussion

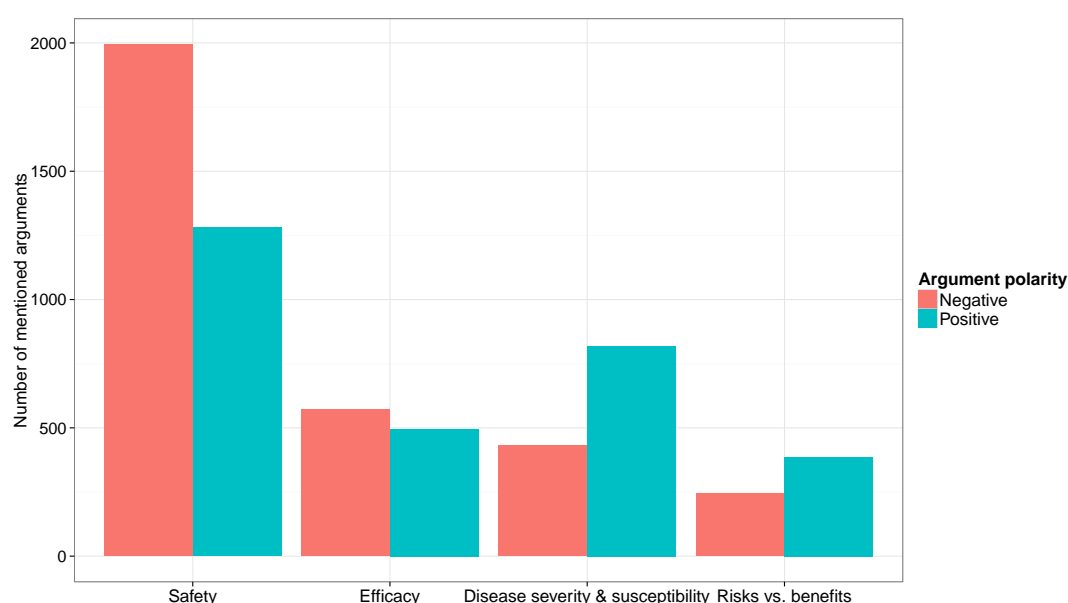
### 2.3.1 Descriptive analysis

The sample included 340 threads comprising 6544 posts generated by 1729 users of which 97.7% were females. Threads had on average 19.25 posts ( $SD = 55.30$ , range = 10–1031). 76.02% (4975/6544) of the posts mentioned at least one vaccine type or discussed pediatric vaccinations in general; they were generated by 1586 users. These posts included 5795 mentions of vaccine types or concerned pediatric vaccinations in general with an average of 3.65 mentions per user ( $SD = 7.09$ , range = 1–175). Figure 3 reports the counts for all vaccine types mentioned in the posts.



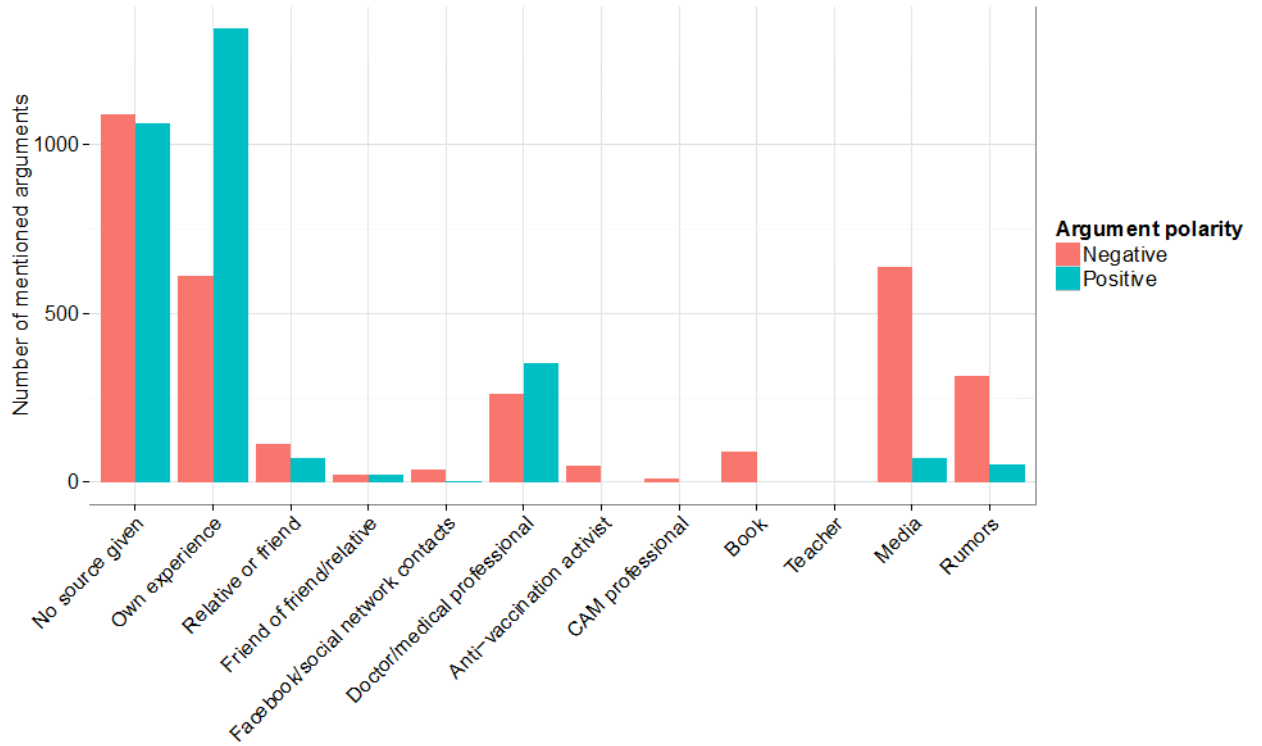
**Figure 3.** Counts of vaccine types in all content-analyzed posts

72.52% (3608/4975) of the posts mentioning at least one vaccine type presented one or more argument/claim; they were generated by a total of 1356 users. These posts mentioned a total of 6223 arguments with an average of 4.58 arguments per user (SD = 11.40; range = 1–329). Figure 4 shows the occurrence of positive and negative statements for each argument type/category. There were slightly more negative (52.1%, 3242/6223) than positive arguments. Among all posted arguments supporting a negative position, 61.5% were about the side effects, 17.7% related to the efficacy, 13.3% and 7.5% to the disease severity and susceptibility and the risks vs. benefits respectively. Fear and skepticism toward vaccines become more visible after looking at the distribution of arguments supporting a negative position (Appendix 2). The most frequently occurring statements were related to the “severity of vaccination side effects”, stating that it “may cause autism” or “contains dangerous chemicals” and that it “is not efficacious”.



**Figure 4.** Distribution of negative and positive positions by argument type

Regarding the sources of information, 75.02% (2707/3608) of the posts having one or more arguments/claims cited one or more source for the mentioned argument; they were generated by 1152 users. 4067 mentions of sources were recorded with an average of 3.53 per user ( $SD = 8.46$ ; range 1–237). The most frequent sources were users' own experience with a 48.1% (1956/4067) share, media with 17.5% (710/4067), doctor or medical professional with 15.1% (615/4067), rumors 8.9% (364/4067), and relatives or friends with 4.6% (186/4067), reiterating that vaccination-related Web 2.0 platforms are dominated by personal narratives and media-derived information (Betsch et al., 2013). Figure 5 shows the distribution of all mentioned arguments on the forums by the argument polarity (negative vs. positive) on source types. As mentioned before, the “no source” and “own experience” categories are prevalent for both positions. However, it is worth noting that negative positions are attributed to multiple sources compared to the positive positions, with “media” and “rumors” frequently cited for negative positions. Unexpectedly, both positions cite medical professionals with a marginal win for arguments with positive positions.



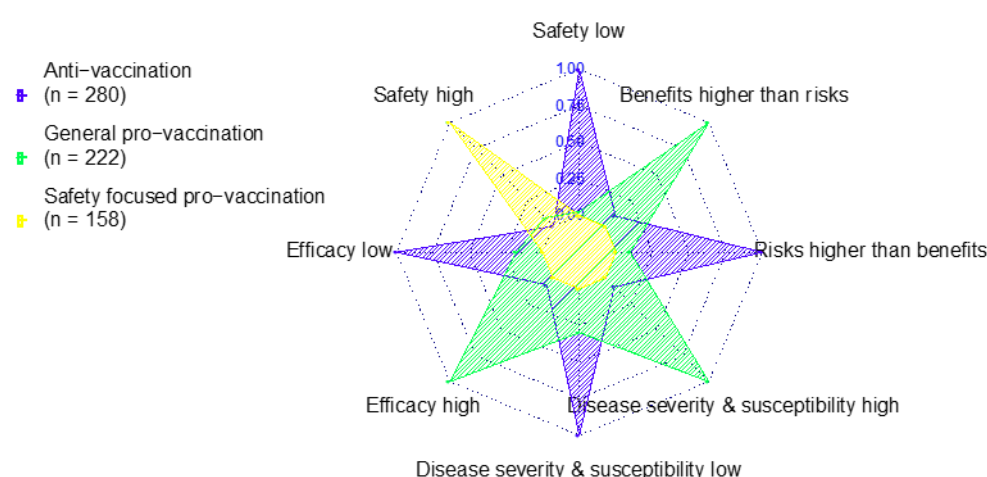
**Figure 5.** Distribution of negative and positive positions for arguments by source type

### 2.3.2 User clustering based on arguments

Six hundred sixty users were part of the clustering based on arguments, representing almost 48.7% of the total users who posted claims in the forums. These users posted 5254 arguments, which made 84.4% of the total arguments posted. Three clusters/groups emerged (Figure 6 and Table 1 in Appendix 3):

- a “general pro-vaccination” group ( $n = 222$ ), posting arguments that covered all 4 argument classes and making mainly positive statements;
- a “safety-focused pro-vaccination” group ( $n = 158$ ), who posted arguments which mainly fell into the class of vaccine safety concerns, emphasizing the safety of the discussed vaccines and denying their negative side effects;
- an “anti-vaccination” group ( $n = 280$ ), who posted arguments spanning all 4 classes, highlighting the negative aspects of the discussed vaccines from multiple perspectives.

The anti-vaccination group generated 55.1% of the posted arguments, while 30% and 14.9% were generated by the general and the safety-focused pro-vaccination groups respectively. On average, the anti-vaccination group posted 10.35 arguments with  $SD = 22.84$  while both pro-vaccination groups had a mean of 6.2 arguments with  $SD = 5.88$ . This suggests that the anti-vaccination group is highly active and present in the forums compared to the two other groups, contrary to previous findings that Web 2.0 platforms were dominated by vaccination-favorable users (Pereira et al., 2013).



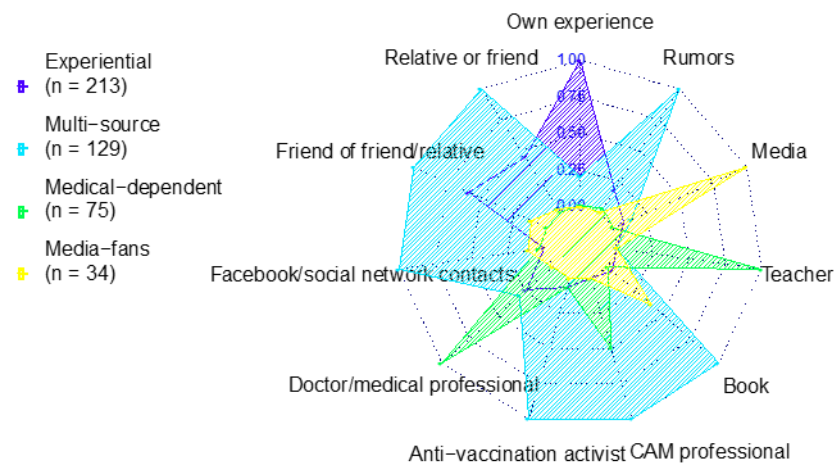
**Figure 6.** Radar chart demonstrating standing-out features of the three groups that emerged from the argument clustering

### 2.3.3 User clustering based on sources of arguments

Four hundred fifty-one users were part of the clustering based on users' mentioned sources of arguments, representing 39.2% of the total users who mentioned at least one source of their posted arguments. These users mentioned 3117 sources, representing 76.6% of the total sources mentioned in the forums. Four clusters/groups emerged (Figure 7 and Table 2 in Appendix 3):

- the experiential group (n = 213), having one's own experience or someone's close as a main source for arguments about vaccines;

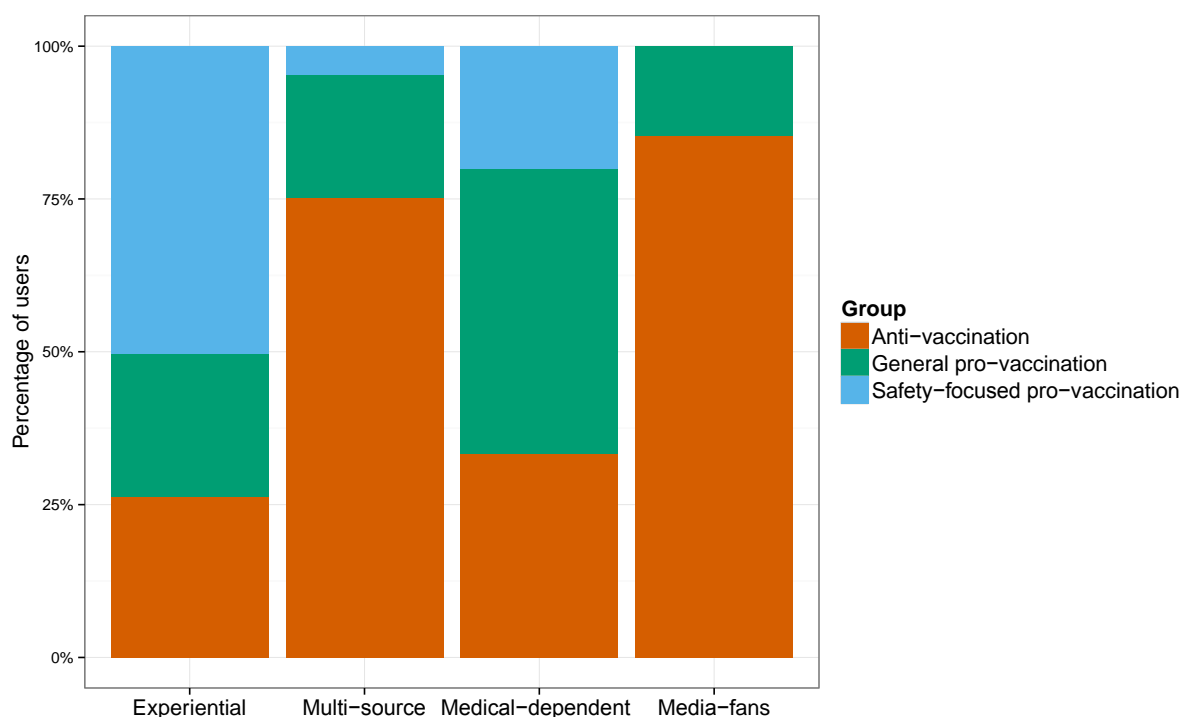
- the multi-source group (n = 129), citing a wide range of sources to back up its arguments;
- the medical-dependent group (n = 75) that cites doctors or medical professionals as the main source of its arguments;
- the media-fans group (n = 34), mentioning media sources such as traditional media (i.e. TV) and the Internet.



**Figure 7.** Radar chart demonstrating standing-out features of the four groups that emerged from the source clustering

Comparing the clustering with the aggregated count of all mentioned arguments by argument polarity and source (Figure 5), two observations could be noted. The first one is related to how the clustering solutions preserved or echoed the dominant associations or spikes evident in Figure 5, although only 84.4% and 76.6% of the arguments and sources respectively were used in the clustering procedure and attributed to less than 50% of users in the forum. The second one is related to the ability of the clustering procedure to provide richer semantics, going beyond the simple two opposing views (pro and anti) depicted in the argument polarity in Figure 5. Identifying three groups that incorporate the argument

category/type into their characterization (e.g. safety-focused pro-vaccination group) is the adjunct of the cluster methodology. The same can be said of the source clustering, which generates source categories semantically related and close to each other. Hence, the distribution presented in Figure 5 provides a rather traditional way for content of various kinds to be analyzed, whereas the clustering procedure goes beyond each individual feature and provides richer semantics as groups/clusters are generated based on multiple features. The connection between Figure 5 and clustering solutions becomes more visible when we link the argument and the source clusters in Figure 8.



**Figure 8.** Membership in argument cluster group by source cluster group

Figure 8 shows how the 3 argument clusters are distributed on the 4 source clusters. This association between both clustering procedures is based only on users who were part of both clustering procedures. It can be seen that users who belong to the media-fans group mostly also belong to the anti-vaccination group. This can be explained by recent studies

that found that Internet users looking for vaccine-related information are more likely to find critical than favorable results (Ward et al., 2015). Another recent study (Capanna et al., 2015) found that, following a negative media event about the side effects of influenza vaccination in Italy, a decrease of up to 18% in vaccination rates was recorded compared to the previous season. Similarly, users who use diversified sources belong predominantly to the anti-vaccination group, indicating that, as previous studies found, even when more than one source is used, the one that delivers vaccine-critical information may have the strongest impact, although other factors that were not the object of the present study could also play a role. In contrast, the experiential group had more than 2/3 of its users posting predominantly pro-vaccination arguments, with 50% of the users in the experiential group being also members of the safety-focused pro-vaccination group. This may signal that social norms supportive of the vaccination may play an important role in fostering the acceptance of children's immunizations (Oraby et al., 2014). As for the medical practitioners-dependent group, there was a more even distribution among the three groups, which may reveal that the anti-vaccination group employs medical professionals as one of its sources. This goes along with previous findings about medical professionals advising against vaccinations, which has also been found to be an important risk factor for suboptimal vaccination (Schmidt & Ernst, 2003; Zucs, Crispin, Eckl, Weitkunat, & Schlipkötter, 2004).

## **2.4 Limitations**

In this study, we have sought to quantitatively report on which arguments and sources about pediatric vaccinations are shared by users of three popular online forums in Italy. Three main limitations of this work are worth mentioning. First, since it was not always clear which post responded to which, it was impossible to perform a social network analysis, which would have shed light on users' connectivity and social entourage. Second, to encapsulate and account for the majority of the information shared, the definitions of the clusters were left rather broad and therefore do not allow for recovering a detailed description of users' utterances. Third, the time-span of our study was restricted to the period between January 2008 and June 2014. Several vaccination-related events have



happened since then and, consequently, may have affected users' arguments and related sources. Also, new users with different experiences might have subscribed to the forums after-wards.

## **2.5 Implications and conclusions**

The growing popularity of Web 2.0 applications for health-related needs and the mushrooming presence of anti-vaccination users' in such an environment urges researchers and public health stakeholders to consider possible strategies to contain the viral spread of inaccurate information on vaccinations (Bégué, 2012) and limit possible attempts by immunization opponents to draw other users over.

Automated systems and tools for the detection of disease out-breaks or epidemic threats (Linge et al., 2009) trained on targeting the detection of false information and rising public concerns about medical topics such as vaccination (Simpson et al., 1995) could be a solution. Information extracted from forums, social media and other online platforms provide huge insights about people's concerns and opinions about medical topics (Mollema et al., 2015). Given the high share of disseminated information, we believe that automated strategies to analyze and detect health concerns would provide a scalable method for public health authorities to localize problems and intervene promptly. In this study, cluster analysis was used as a tool to identify users that share similar posting patterns with respect to the cited arguments and sources about pediatric vaccines. This allowed us to study and discuss the different strategies followed by each group, especially the anti-vaccination group that mainly contributes to the spread of inaccurate/dangerous information about pediatric immunizations. Other approaches and types of analyses that could complement and benefit our study have been employed in the literature. An example of such strategies is social network analysis, which has been

employed both in the epidemiological literature for the detection of disease outbreaks (Christakis & Fowler, 2010) and in the sociological literature to assess the role of homophily in the spread of vaccination sentiments (Brunson, 2013).

Until we achieve automation, other approaches represented by increasing the quality and frequency of vaccination advocates' presence online, adapting their communication to a language that is suitable for the online environment, and identifying and directing uninformed users to the appropriate and trusted information sources would also help. Since users accessing Web 2.0 platforms for vaccination-related reasons often do so to find experiential evidence, future health communication efforts should be devoted to incorporating tangible proof when presenting claims about the safety and efficacy of the vaccination as well as the risks posed by the disease. This could be considered within a strategy to immunize users against the critical arguments they are likely to encounter in the online platform they are entering (e.g. by means of the inoculation theory). In light of previous studies which found that vaccination sentiments expressed online and local vaccination rates are strongly correlated (Salathé & Khandelwal, 2011), knowing which information is shared online on the topic of pediatric vaccinations becomes apriority that health authorities can no longer overlook

## Chapter III

Addressing issues of vaccination literacy and psychological empowerment in the measles-mumps-rubella (MMR) vaccination decision-making: A qualitative study

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### *Chapter III*

#### *Abstract*

**Background:** Whether or not to vaccinate one's child is one of the first health-related decisions parents have to make after their child's birth. For the past 20 years, the share of parents choosing not to immunize their children has increased in many countries, for various reasons. Among these, rumors affirming that vaccinations contain dangerous chemicals or might trigger severe chronic diseases have negatively affected parental attitudes towards pediatric immunizations, particularly the vaccination against measles, mumps and rubella (MMR), raising a number of public health concerns. The primary aim of this qualitative study is to understand what drives parents' decision, giving special attention to vaccination literacy and psychological empowerment in such a context.

**Methods:** Twenty individual semi-structured interviews were conducted in the Canton of Ticino (Switzerland) between January and June 2014. Participants were either mothers or fathers of children less than 1 year old living in Switzerland. An inductive thematic analysis was performed to identify the main themes with regard to vaccination literacy and psychological empowerment in the MMR vaccination decision-making.

**Results:** Parents' reports yielded four main themes: (a) the paradox of the free choice, referring to the misinterpretation of current vaccination policies; (b) giving up the power, pointing at the outcomes of a low perceived competence; (c) a far-reaching decision, reflecting the importance attributed to the MMR choice and the different levels of impact the decision can have; (d) the demand for shared-decision making, referring to the parental needs in relation to the child's healthcare provider.

**Conclusion:** Understanding what drives parents' management of their children's immunization schedule in terms of vaccination literacy and psychological empowerment can help health professionals to communicate more effectively with parents in order to facilitate an informed decision, and stakeholders to design tailored health education programs and materials. This can ultimately help increase the coverage of the MMR vaccination.

### **3.1 Background**

Measles is an infectious respiratory disease, which can lead to severe complications particularly in children under the age of 5 and adults over the age of 20 (Centers for Disease Control and Prevention, 2015a). In developing countries, measles is still one of the leading causes of death among children, although a safe, efficient and relatively inexpensive two-dose vaccination is available (World Health Organization, 2015). The most common measles-containing vaccine is the MMR vaccine, which also protects from mumps, a disease characterized by swelling of the salivary glands, and rubella, an infection that can often lead to serious complications in the fetus if acquired by an expecting mother (CDC, 2015a). To reach herd immunity, health authorities recommend that 95% of the population be vaccinated (WHO, 2015).

In most developed countries, parents are recommended to immunize their children against MMR, but the final decision is theirs. This policy, which calls for an informed, autonomous decision, assumes parents possess the relevant and accurate information regarding both the risks and the benefits of the vaccination compared to the disease, the skills to judge what is more appropriate for their child, and the motivation to engage autonomously in such a decision. In other words, parents are expected to be knowledgeable and empowered in order to make their choice, whether or not their final decision will meet the country's official recommendations. Indeed, even with a sound knowledge and a high level of engagement in the decision-making, different factors and cognitive processes might lead to a biased judgment, such as omission biases (Meszaros et al., 1996). Although making vaccination compulsory may be seen as a strategy to boost adherence to vaccination programs, compliance with vaccination schedules in Europe is high even when vaccinations are merely recommended (Ciofi Degli Atti et al., 2004; Haverkate et al., 2012).

As in most European countries, the MMR vaccination is not compulsory in Switzerland. The country is committed to the goal of eliminating measles and rubella in the European Region of the World Health Organization by 2015. However, it currently displays suboptimal MMR coverage, making measles still locally endemic (Ciampa et al., 2013; Delaporte et al., 2011; Richard & Masserey, 2009). Recent data from the Swiss

Federal Office of Public Health (FOPH) show that only 86 % of 2-year-old children have received the two doses that make a full MMR course (Federal Office of Public Health, 2015).

Between 2006 and 2009, Switzerland experienced the highest measles incidence rate of Central and Western Europe, making up 29% of all measles cases that occurred in the 32 European countries reporting to the same surveillance network (ECDC) (Richard & Masserey, 2009). Despite a widespread prevention campaign, measles cases in Switzerland have nearly doubled in 2013 compared to the previous year (Federal Office of Public Health, 2015). In addition, Switzerland constitutes a potential source of imported measles for other countries in Europe and elsewhere, such as Germany, Denmark, England, and the United States (Richard & Masserey, 2009).

Research has extensively studied drivers and barriers of parental vaccination decisions. The most significant predictors of vaccination behavior include perception of the risks posed by the disease and the vaccination side effects (Bennett & Smith, 1992; Betsch & Wicker, 2012; Bond, Nolan, Pattison, & Carlin, 1998; Spier, 2001; Tarrant & Thomson, 2008), beliefs and attitudes towards the disease and the vaccination (Brown et al., 2011; Gilkey et al., 2014; Heininger, 2006; Lavail & Kennedy, 2013; Yaqub et al., 2014) and its efficacy (Roberts et al., 1995), and safety concerns (Andreae, Freed, & Katz, 2004; Bardenheier, Yusuf, Schwartz, et al., 2004; Streefland, 2001). An extensive literature has also acknowledged the role of trust in medical professionals, health authorities, and governments (Austin, Campion-Smith, Thomas, & Ward, 2008; Cooper et al., 2008; Larson, Leask, et al., 2013; Larson, Wilson, Hanley, Parys, & Paterson, 2014; Larson, Smith, et al., 2013; Mills, Jadad, Ross, & Wilson, 2005; Tarrant & Thomson, 2008), and social norms (Oraby et al., 2014). In addition, religious beliefs (Simpson et al., 1995), hesitancy (Dubé et al., 2014), publicity by anti-vaccination groups (Bean, 2011; Blume, 2006; Meyer & Reiter, 2004; Tafuri et al., 2014) and the rise of complementary and alternative medicine (CAM) have been reported as playing a crucial role (Ernst, 2002; Harmsen et al., 2013; Simpson & Roman, 2001; Zuzak et al., 2008). The pediatrician's information (Smailbegovic, Laing, & Bedford, 2003) and communicative style during vaccination recommendation (presumptive vs. participatory; Opel et al., 2013) can also be

influential on the decision. Mixed results are available for the role of demographic variables such as education (Borràs et al., 2009; Prislín et al., 1998; Taylor et al., 1997, 2002), age, race, marital status and number of children (Casiday, 2007; Kriwy, 2012; Luman et al., 2003). Furthermore, evidence suggests that immigrants are more likely to adhere to vaccination recommendations compared to the local population (Hansen, Koch, Wohlfahrt, & Melbye, 2003; Markuzzi, Schlipköter, Weitkunat, & Meyer, 1997; Mikolajczyk, Akmatov, Stich, Krämer, & Kretzschmar, 2008). Knowledge has also been identified as an indirect driver (Angelillo et al., 1999; Baker, Wilson, Nordstrom, & Legwand, 2007; Betsch & Wicker, 2012; Borràs et al., 2009; Okoronkwo, Sieswerda, Cooper, Binette, & Todd, 2012; Zingg & Siegrist, 2012).

Within the extensive literature currently available on what informs parental decision regarding childhood vaccinations, several studies have specifically looked at the context of the MMR vaccination, especially after the MMR scare sparked by a Lancet article which claimed a link between MMR and autism in 1998 (Brown et al., 2012; Byström, Lindstrand, Likhite, Butler, & Emmelin, 2014; Casiday, 2007; Dannetun, Tegnell, Hermansson, & Giesecke, 2005). A summary of the most common factors underlying parental MMR vaccination decision making can be found in a recent systematic review (Brown et al., 2010).

Research has shown that a unique set of beliefs and different positive and negative attitudes surround each vaccination and its related disease(s) (Larson, Leask, et al., 2013). Our study aims to explore the reasons that drive parents' MMR vaccination decision, with a careful look at vaccination literacy and psychological empowerment. To our knowledge, this is the first study addressing vaccination literacy and empowerment together in the context of parents' decision to have their child immunized or not. The MMR vaccination features a number of unique characteristics compared to other childhood vaccinations – such as being at the center of the autism controversy (Maisonneuve & Floret, 2012). Moreover, administering this vaccine can be seen by parents as the closest thing to a natural infection, since it is made of live attenuated viruses of its three target diseases (CDC, 2015b). Studies have also shown that postponing this vaccination may have serious consequences for future outbreaks (Dannetun et al., 2004).

*3.1.1 Theoretical background*

Since parents have the final say on their children's immunization, the MMR vaccination decision is extremely sensitive to individual differences. A number of theories have addressed such behavioral differences from a variety of perspectives. Among these, the Health Empowerment Model provides a theoretical framework that considers health literacy and psychological empowerment as two equally important and independent predictors of health behavior (PSchulz & Nakamoto, 2013). The model has been applied to a number of contexts, including eHealth interventions (Camerini & Schulz, 2012) and studies on chronic patients' self-management (Camerini et al., 2012). Recently, its application to the context of vaccination behavior has been advocated to explain parental resistance against physicians' professional standards, suggesting the potential danger of vaccination misinformation when this is coupled with high parental empowerment (Schulz & Nakamoto, 2013).

Nutbeam (2009) defines health literacy as "the capacity to acquire, understand and use information in ways which promote and maintain good health" (Nutbeam, 2009). Schulz & Nakamoto (Schulz & Nakamoto, 2013) stress the multidimensionality of this concept, defining it as a set of four sub-dimensions: (a) functional literacy, (b) declarative knowledge, (c) procedural knowledge, and (d) judgment skills. Similar to health literacy, psychological empowerment is an intrinsic motivational construct of the individual manifested in four cognitions (Kraimer, Seibert, & Liden, 1999; Spreitzer, 1995, 1996): (a) meaningfulness (the extent to which what one does is perceived as being important), (b) competence (one's perceived competence to carry out an action), (c) impact (the perception of making a difference through a certain action) and (d) self-determination (the extent to which what we do is perceived as autonomous). Although the term empowerment originally focused on the individual, the collective, and the organizational levels (Christens, 2013), our study shall be concerned with the individual level only. Ideally, people will possess the adequate knowledge and skills to manage their own care, but also the commitment and motivation to make autonomous and impactful decisions. For a more



thorough description of the Health Empowerment Model, see Schulz and Nakamoto (Schulz & Nakamoto, 2013).

In the context of parental vaccination decision, health literacy can be studied in terms of both knowledge about vaccinations and ability to find, judge and use the information encountered, in light of the high amount of inaccurate material which parents can be exposed to (Robert Koch Institute, 2007). Knowledge can be further split into declarative and procedural. Declarative knowledge includes, for instance, knowledge about infectious diseases, the availability of vaccines, or the likelihood and severity of their side effects. Procedural knowledge entails notions such as knowing how and when to get vaccinated against infectious diseases (Diviani et al., 2012).

Adjusted to the context of parental vaccination decision-making, the four sub-dimensions of psychological empowerment can be operationalized as following: (a) meaningfulness will refer to the degree to which an individual thinks that making a vaccination decision regarding his or her child is an important issue; (b) competence will refer to the degree to which an individual feels able to make a sound vaccination decision; (c) impact will refer to the degree to which an individual feels that making a decision over the vaccination can generate a number of outcomes; (d) self-determination will refer to the degree to which individuals think that their vaccination decision is solely determined by themselves. A study was conducted using semi-structured interviews with parents in order to explore the factors driving parental MMR vaccination decision with regards to vaccination literacy and psychological empowerment.

## **3.2 Methods**

### *3.2.1 Recruitment and participants*

Qualitative methods are most appropriate when a better understanding of a phenomenon is sought (Britten, 2011), or when a theory needs to be built. Individual interviews rather than focus groups were chosen as they allow to obtain a deeper individual understanding of parents' vaccination literacy and empowerment in the MMR vaccination decision making.

Participants were recruited in the Canton of Ticino (Italian-speaking Switzerland). To maximize the variability of our sample's experiences, we employed a diverse recruiting system. Invitation flyers were sent to pediatricians and gynecologists, distributed at local public and private nursery schools, pre-schools, supermarkets, pharmacies, yoga and baby splash classes. In addition, invitations were circulated in a number of public spaces and printed in a number of local newspapers. Participation was optional and participants received a 20.- CHF shopping voucher as compensation.

Eligibility criteria for this study included: (a) being parent of at least one child under the age of 12 months (since the administration of the first dose of the MMR vaccination is recommended in Switzerland when the child turns 1-year-old, our inclusion criteria allowed to meet parents during their vaccination decision-making); (b) being a permanent resident in the Canton of Ticino.

### *3.2.2 Data collection*

We conducted 20 face-to-face, semi-structured individual interviews in Italian, which lasted approximately 30 min each. We used semi-structured interviews in order to have a flexible grid of structural and open questions, allow each interviewee to describe his or her experience and introduce new themes spontaneously. The interview guide was developed on the basis of the Health Empowerment Model (Schulz & Nakamoto, 2013) to elicit detailed information on: (1) confidence in one's MMR vaccination decision; (2) vaccination literacy, including general beliefs, procedural knowledge, subjective knowledge, perceived outcomes of MMR, and information-seeking behaviors (Griffin, Dunwoody, & Neuwirth, 1999; Rimal & Juon, 2010); (3) psychological empowerment, according to its conceptualization into the four sub-dimensions of meaningfulness, impact, self-efficacy, and self-determination (Schulz & Nakamoto, 2013); (4) social influences; (5) reactions to MMR-related information; (6) usage of complementary and alternative medicine (CAM); (7) risk perception of both measles and MMR side effects (comprising severity and susceptibility of their respective consequences); (8) barriers to the decision. See Appendix 4 for a detailed interview schedule containing all questions.

The vast majority of the interviews were conducted by the first author, who has a background in social anthropology, either at parent's house, workplace, or at the University, according to their preference. To assess children's age and collect parents' socio-demographic characteristics (age, origin, education, number and age of children), a short questionnaire was sent by email to each participant upon completion of the interview.

If participants explicitly gave us permission, they were sent official information leaflets on measles and the MMR vaccination together with the gift card and a debriefing letter after the interview.

Data collection and data analysis were carried out simultaneously over a period of 5 months beginning in January 2014. Data collection ceased once data saturation was reached, that is when it was decided that additional interviews would not yield new data, but only confirm what was found in previous interviews (Guest, 2006).

### *3.2.3 Analysis*

Each interview was recorded, using a digital voice recorder, and transcribed verbatim by the main researcher and the research assistant (both native Italian speakers) within 3 days from completion of the interview. The transcripts were read several times by the main researcher to become familiar with the content, and they were later entered into NVivo for the coding (QSR International Pty Ltd. Version 10, 2012). Both transcription and analysis of the interviews were conducted in the original language (Italian) to avoid missing significant elements during the translation process. An inductive thematic approach (Thomas, 2006) was used for the analysis of the data. Meaningful utterances were grouped and later categorized under several labels. Labels were subsequently organized hierarchically (Braun & Clarke, 2006), and similar labels were then gathered into bigger themes. Preliminary themes, labels and utterances were then discussed with two senior qualitative researchers who provided feedbacks in relation to the ongoing analysis. At the end of this process, all transcripts were read again to establish logical links between different themes. The results of the inductive thematic analysis will be described in the following section, while they will be interpreted in the discussion section by making the link to our research question.

### **3.3 Results**

#### *3.3.1 Participant characteristics*

Demographic data are summarized in Table 1. Most participants were mothers, had more than one child, and were in their thirties (age range 23–42). Regarding education, either a university degree or a professional university certificate was held by nearly two thirds of the sample. Immigrants represented a large percentage of our sample, which is in line with current statistics about the migrant population in Switzerland (estimated at 35%) (Swiss Federal Statistical Office, 2015). On the basis of their reports, participants were classified as either being opposed ( $n = 3$ ), favorable ( $n = 13$ ), or undecided ( $n = 4$ ) with regards to the MMR vaccination.

**Table 1.**  
*Characteristics of the participants*

N=20 participants	
Gender	15 mothers and 5 fathers
Age	23-42 years old (M = 34) 3 participants: $\leq 29$ years old 14 participants: 30-39 years old 3 participants: $\geq 40$ years old
Origin	13 from EU, 2 from non-EU countries, 5 from Switzerland
Level of education	2 secondary school, 4 high school education or equivalent, 14 university or professional university degree
Number of children	6 participants: 1 child 12 participants: 2 children 2 participants: 3 children
Attitude towards the MMR vaccination	3 participants: opposed 13 participants: favorable 4 participants: undecided

The analysis of the transcripts yielded four main themes: (a) the paradox of free choice, (b) giving up power, (c) a far-reaching decision, and (d) the demand for shared-decision making. Parents' perceptions with regards to the likelihood to catch measles varied across the participants. Most parents agreed that measles is a highly infectious disease that can spread even faster if the child frequents other children, and learned from different sources that the disease is "making a comeback". Undecided and vaccination-opposed parents, on the other hand, believed that their children were not likely to catch it, and expressed a preference for either natural immunity or safer alternatives to the MMR vaccination as a form of prevention. Only few, highly educated pro-vaccination participants cited the possible serious consequences of measles. The majority of parents found, instead, that measles was not a serious disease, referring to it as a type of "chickenpox" that can only have serious consequences in adults. Experience seemed to shape the perception of the severity of measles among those participants who had contracted the disease in the past. Pro-vaccination parents felt that their children were not likely to incur in side-effects due to the vaccination and they did not consider them to be

serious, while undecided and opposed participants perceived them as highly probable and severe.

### 3.3.2 The paradox of the free choice

Unlike some of its neighboring countries (Haverkate et al., 2012), Switzerland does not have any mandatory vaccinations, but parents are recommended to follow a specific vaccination schedule for their children. The MMR vaccination is among the recommended vaccinations. However, a main finding was that parents differed in their interpretation of current vaccination policies in Switzerland with regards to the MMR vaccination, with some misinterpreting the ultimate scope of the free choice in the vaccination decision, i.e. parental empowerment. The view that MMR would be mandatory if measles were a serious disease, and not merely recommended by health authorities, dominated the reports by vaccination opposed parents.

*“I say, if it was really a serious disease that has to be absolutely eradicated and never appear again, I believe all nations would agree on vaccinating children. [...] When they asked me if I wanted to vaccinate him against rubella, I did not feel like it. I said no. [...] I listened to their opinion, but I did not listen to their advice. In the end, I decided to follow what my husband and I had decided to do”.  
(Mother, 38, Ticino, Secondary School, Opposed)*

The same mother, guided by her perception that catching measles was not likely, expressed a preference for either natural immunity or safer alternatives to the MMR vaccination as a way to prevent her child from getting the disease:

*“If there was a measles outbreak somewhere... well, I would pay more attention. But I have the impression that everything always works by hand contact, doesn't it? I have this idea in mind, that if I teach him (the child) to regularly wash his hands, since he also likes water a lot, he will be protected... This is my prevention”.*

Some parents believed that Switzerland had both compulsory and recommended vaccinations, and translated the non-compulsoriness of the MMR vaccination as further evidence that it was not a necessary preventive measure:

*“Anyway, I said, let’s do the basic ones, the almost mandatory ones, those. Whether I want or not? I don’t want! Because if you tell me ‘if you want’ it seems optional, an optional vaccination, for me it seems there is no risk, no? If it is optional... come on! [...] And since I will make the decision with my wife, we often go and look for information. We look on the Internet, we only look on the Internet”.*  
(Father, 28, non-EU, University, Opposed)

On the other hand, parents that had a positive attitude towards the MMR vaccination saw current policies as a sign that the vaccination is important to protect children from unnecessary illness.

*“If they offer a vaccination, there must be a reason. I do not want him to get a disease that is out there. Vaccinating is life”.* (Father, 35, Non-EU, Obligatory School, Favorable)

### 3.3.3 Giving up the power

A number of parents reported that they perceived themselves to be unable to make a sound decision for their child. As a consequence of this feeling, some of them reported that they gave up their role as the agent in the management of their child’s health, while others opted for an autonomous decision anyway. Some completely relied on other decision-makers such as the pediatrician or followed what their parents had done with them or was prescribed in their original culture, while others made a gut-driven decision. To some parents, ability to make a decision included the skills needed to grasp the official information received by health authorities and health professionals. As this language mainly includes statistical information on the likelihood of getting the disease or

experiencing vaccination adverse events, parents reported a preference for narrative information on the MMR vaccination, which they described as easier to understand.

*“Moreover, my problem is that I don’t have a scientific background. And when you hear... When you read this [official] information, you realize they all start from the results of some statistical tests that they did on vaccinations. Maybe the base is wrong... because one starts from certain statistical data, and the other starts from the same, but not keeping into account other data”. (Mother, 34, EU, Professional University, Opposed)*

Some parents reported that they felt overwhelmed by fear of possible side effects of the MMR vaccination, sometimes after becoming familiar with anti-vaccination campaigners and other parents’ personal experiences. These parents believed that a key skill to be competent in the decision is the ability to assess the reliability of the information received and its quality. For these parents, it becomes difficult to decide which information source to trust. As a consequence, they reported that the decision over the MMR vaccination was emotionally-driven. The mother cited above experienced fear when she was informed, during one of the conferences held by antivaccination doctors she regularly attended, about the severe side effects that the vaccination might cause. She described her decision as follows:

*“Since you do not know how these statistics are made and if they are reliable or not, you say: it’s not possible that in the end they reach completely different results. Should I trust one or the other side? And so sometimes... you end up just listening to your gut. [...] If you go to one of their conferences, they explain what can happen to the child, they explain everything. And then you start to fear... Because they have interviewed mothers whose children, just after the shot, could not move, or could not speak”. (Mother, 34, EU, Professional University, Opposed)*



Other parents reported that one can perceive himself or herself as competent only when holding accurate information on the MMR vaccination and on the likelihood to catch the disease. Lacking this information, and worried that they could make the “wrong” decision, they did not want to have the final say on it, but preferred to devolve it upon the pediatrician.

*“If I had to guess which percentage of vaccinated children get sick, I don’t know where... I don’t know the percentage. So I would ask the doctor. I’d look on the Internet, but ultimately before making a decision I would ask the doctor anyway”.*  
(Mother, 41, Ticino, University, Favorable)

Entrusting this decision upon a medical professional without questioning it and refusing to be involved can, however, have dangerous consequences, as some parents also expressed a preference for natural immunity after being recommended by doctors and nurses to avoid the vaccination.

*“To be frank, the pediatrician once told me “There are certain vaccinations that I recommend, others that I don’t. And this is about vaccinating for something that no longer exists, isn’t it? So, honestly, I do not recommend”. And at that time I didn’t know much. I was very busy, too. So I listened to him”.* (Father, 28, non-EU, University, Opposed)

Other parents felt that, since they lacked the training doctors usually have, the MMR vaccination decision could only be driven by one’s family tradition or by social norms related to the original culture. In this case, parents had a propensity for what had been done with them when they were younger, or for what was socially prescribed in their original culture. Participants with an immigration background held a number of health beliefs related to their home healthcare system where vaccination was compulsory or where pro-vaccination social norms were stronger. For these parents, vaccinations in general represented an issue that is never discussed, as immunizations were recommended by a

trusted authority. They did not question the importance of the vaccination, as vaccinating was also culturally prescribed in their home country.

*“In Brazil, vaccination is a matter of culture, everyone has his or her own vaccination book, and if you do not fill it, then you are not accepted. It never happens that someone opts out. If there is a vaccine, we just do it. We never discuss about it. We did not study medicine, we just have to trust doctors. [...] For me vaccination comes at the first place, possibly because of my culture, this is how I grew up. It is very important to us, to all Brazilians. (Father, 35, Non-EU, Obligatory School)*

Perceived competence in the MMR vaccination decision differed among our participants. Moreover, the idea of competence was also seen by some as related to the ability to make an autonomous decision. Some parents mainly defined it as the set of skills necessary to understand the information provided by official sources (statistics). For others, it is the ability to distinguish reliable from non-reliable information, particularly when contradictory information is presented. Some stated that feeling competent was about being well-informed on the risks and benefits of the vaccination and the risks of the disease(s). For some parents, perceived competence is related to the lack of medical training, and in this case issues of vaccination tradition and social norms can play a strong role, since the decision will be ultimately made in accordance with what was prescribed by the original culture.

#### 3.3.4 A far-reaching decision

The MMR vaccination decision was generally cited as one of the most significant decisions made since the child's birth. When asked about what importance meant to them, some parents spontaneously reported that by deciding to give the MMR vaccination to their child they would contribute to accomplishing a global goal and get closer to the eradication of the three target diseases.

*“My main aim is to try to eradicate these diseases. The last time I went to the doctor, I saw a poster that read: in South America, measles has been... I mean, it does not exist anymore. In Switzerland is still present instead”. (Mother, 36, Swiss-German, University, Favorable)*

For others, the vaccination decision is central because it concerns the child's health. The impact of the decision, in this case, may be of two types: on the one hand, administering the vaccine is perceived as injecting something in the child's body which might cause harm, while on the other hand, failing to do so might result in the child experiencing a dangerous illness.

*“I did not feel like it, because I felt that I was injecting something harmful. Inside myself, I did not feel like it. So I preferred to listen to these (anti-vaccination) groups. [...] But, obviously, I don't know if he gets measles tomorrow and he dies (as a consequence). This is the most important choice, because it is just about his life”. (Mother, 34, EU, Professional University, Opposed)*

Further support for the importance of this choice rests on some parents' experience that deciding over the MMR vaccination might affect not only the child's social life, but also the family life-style.

*“I think that taking him to the nursery school is the most important decision, the one that has the greatest influence on his life right now. But the vaccination is important alike, because it also affects our travel plans. We are frequent travelers, we often go to Africa or Asia”. (Mother, 34, EU, Professional University, Favorable)*

Some parents reported that complying with official vaccination recommendations is a matter of common good and respect towards society, and in this sense they suggested that educational institutions and health authorities should adjust their vaccination policies in

order to prevent free-riding and putting at risk those children who cannot be vaccinated for medical reasons.

*“To my mind there should be one guideline. There should be a model that regulates the admission of children with certain requisites at school. Because I think that, if your child is vaccinated, it also protects the others. So it seems to me that this has a scope... a bit more social [...] I say... respect! You cannot have everything, you cannot decide this and later exploit public structures where there are norms, right? This is inconsistent to my mind”. (Mother, 40, EU, University, Favorable)*

Parents reported that this social aim is indeed missing among anti-vaccination parents, who merely worry about their own children in an individualistic fashion.

*“For them [vaccination opposed parents] it is not important that, unless everyone is vaccinated, we get the disease. I mean, the collective scope, they do not even consider that. They look at their child and say - this way is better, to our opinion”. (Mother, 35, EU, University, Undecided)*

Some saw the concept of importance as a synonym of contingency and stress. In this sense, the MMR vaccination decision was seen as a less compelling choice than others, which instead required a long and constant mental reasoning.

*“I don't know if I would say that it is more or less important than deciding over the nursery school... It is definitely less pressing, in the sense that choosing over the nursery school has demanded a more careful consideration than deciding on the vaccination, because its consequences were just more contingent. Vaccinating takes a moment. Deciding whether to send him to the nursery, for how many days, which days and so on, that entails a number of choices that go beyond the contingency of the day of the vaccination. It's a matter of daily life, it's not just confined to a specific moment”. (Father, 31, EU, University, Favorable)*

In sum, the importance of the MMR vaccination decision is seen by parents in terms of its impact on three main levels: (a) the child's health, since he/she is the direct recipient of the vaccination, (b) the family's life-style, as diseases might impede normal activities and habits, and (c) a global/social level, since vaccination is seen in relation to the eradication of the disease and to illness prevention among the child's peers.

### 3.3.5 The demand for shared decision-making

A main finding is that pediatricians were perceived as key elements in the decision-making process, as both a source of information and motivation to engage in the decision. Although the pediatrician was cited as the main source of information by all parents, differences emerged in term of perceived reliability, adherence to and type of recommendation offered. One quarter of the participants, for instance, reported they were not recommended by the pediatrician to vaccinate against measles.

*“The pediatrician has advised me against MMR. He told me he is not really in favor of vaccinations. But I decided I will do it. I have decided to go against the tide!” (Mother, 35, EU, Secondary School, Favorable)*

For most participants, irrespective of their attitude towards the vaccination, previous consultations with the pediatrician around the topic of the MMR vaccination were not perceived as helpful and often left them frustrated, while more involvement from the health authorities' side was also claimed. A number of parents complained that they did not receive quality and tailored advice according to their own skills, neither were they directed to reliable information sources. One mother, for instance, stated that she was dismissed by the pediatrician, who simply recommended her to get informed and return to his office once she had made a decision:

*“When I had to decide for the first vaccination, he told me «Look, I am not so in favor of vaccinations. Look for information and make up your mind. » [...] I wish*

### Chapter III

*I had clearer explanations, especially because what you read is so vast and hard to interpret. I definitely wish I had better information from the pediatrician. [...] He did not even direct me to any sources, he only said "Do as you like". I wish I had a guide instead". (Mother, 35, EU, Secondary School, Undecided)*

Some reported that, in order to feel more confident when making the MMR vaccination decision, they would like pediatricians to devote more time to explaining the risks of the vaccination to parents, by giving a proper lecture on this topic.

*"I think that each pediatrician should set a meeting with all parents and give a proper lecture on this vaccination, not only he alone, but with other doctors. He should give a one-hour lecture, where he explains what he usually does, what he gives to babies when they have this or that problem, where he explains the most common adverse events... I want him to do it so that we feel confident about our decision". (Father, 28, Swiss-Italian, University, Opposed)*

Parents not only suggested that pediatricians should organize regular consultations with them to answer all questions and explain the possible side-effects of the vaccination, but also expressed a desire to attend meetings with both pro- and anti-vaccination doctors, where they could actively participate in the debate.

*"It would be great if the Canton, or the Confederation, could organize conferences with pro and antivaccination doctors, where parents can go and ask all kinds of questions... Because when you go to provaccination events you hear something, and when you go to anti-vaccination conferences you hear something else". (Mother, 34, EU, Professional University, Opposed)*

In terms of discussion, many felt that a lack of debate was a major weakness of their consultation with the pediatrician. One mother reported that the pediatrician did not

engage in discussion on the MMR vaccination with her, and that was among the main reasons why she and her husband were considering switching to another pediatrician:

*“We have never discussed the MMR vaccination with the pediatrician, he only told us there is this vaccine. That’s why my husband and I are challenging him right now... [...] He will probably give us only some material to read when we see him next time”. (Mother, 32, EU, University, Undecided)*

Some parents expressed the desire to make an autonomous decision, but at the same time being guided by the pediatrician’s advice and his/her engagement in discussion with the couple of parents. They felt that competence in such a decision could only be achieved through the pediatrician’s guidance.

*“I would like to feel a stronger engagement by the doctor, to receive adequate information, to have a discussion with my husband and, currently, a discussion with both in the same place. [...] I feel I can decide, but only if guided by someone in the field, by his or her advice”. (Mother, 27, EU, University, Favorable)*

In addition, for some parents, it is not sufficient that pediatricians simply explain the risks and benefits of the MMR vaccination, but it is important that they take a stand on the topic and state their position.

*“I think pediatricians should take a stand... and if they don’t, we should force them to do it. Doctors will obviously say, “It’s your decision, I just explain the risks and benefits”, but for me it’s important that in the end... how to say... they explicitly take a stand”. (Father, 31, EU, University, Favorable)*

Parents complained that they did not receive quality and tailored information by the pediatrician nor were they directly supported in their information-seeking. In addition, what should probably be the core of a shared decision making approach by the

pediatrician, i.e. discussion, was reported by most parents as the biggest deficit of the consultation.

### **3.4 Discussion**

The aim of this study was to qualitatively explore parents' vaccination literacy and psychological empowerment in the MMR vaccination decision-making in the Canton of Ticino, Switzerland. Since the administration of the first dose of the MMR vaccination is recommended in Switzerland when the child turns 1-year-old, we conducted semi-structured interviews with parents of children aged less than 12 months residing in the Canton of Ticino. This helped prevent making erroneous observations that are likely to occur if one asks decision criteria after a decision was made, for cognitive dissonance theory (Festinger, 1962) suggests parents might forget the reasons that guided their decision or justify their behavior on the basis of their later experience.

Regarding vaccination literacy, our results showed that several parents spontaneously reported a belief that the non-compulsoriness of the MMR vaccination in Switzerland is the result of the low likelihood to catch measles that the country enjoys. Furthermore, some parents believed that Switzerland has both compulsory and recommended vaccinations, and translated the non-compulsoriness of the MMR vaccination as further evidence that it was not a necessary preventive measure. This belief can be explained by the fact that some European countries still have both mandatory and compulsory vaccinations. Thus, vaccination literacy has to entail, among other skills such as factual knowledge on the risks and benefits of the vaccination, a correct understanding of the scope of current vaccination policies, since these parents questioned the need for vaccinating (Streefland et al., 1999). Parents' misinterpretations of the aims of the recommended vaccination schedule might be linked to parents' lower risk perception of the disease, which has often been reported among the main predictors of vaccination behavior (Betsch & Wicker, 2012; Bond et al., 1998; Brown et al., 2010; Spier, 2001; Tarrant & Thomson, 2008; Wheelock et al., 2014a), to a refusal of the official schedule or the adoption of unconventional and unsafe preventive measures. Paradoxically, while current vaccination policies are meant to empower parents to facilitate an autonomous



decision (e.g. by means of the free choice), parental misinterpretation of the freedom to decide over the vaccination sets the basis for a dangerous self-management of the child's health. It follows that, if current empowerment strategies are not combined with the promotion of vaccination literacy (i.e. the understanding of current policies and the acquisition of accurate information on the benefits of the MMR vaccination and the risks of contracting diseases such as measles, mumps or rubella), parents are likely to underestimate the benefits and opt for alternatives that clash with official recommendations.

Regarding psychological empowerment, themes related to autonomy (or self-determination) and perceived competence emerged. We found that, in line with previous findings (Austvoll-Dahlgren & Helseth, 2010), parents' perception of lacking expertise about the MMR vaccination and its target diseases, their inabilities to understand medical information, and their perceived incompetence in assessing the reliability of the information encountered may constitute a barrier to their active participation in the decision-making and, thus, to an autonomous decision. Our findings indicate that a perceived lack of knowledge on the MMR immunization and the target disease(s) led some parents to completely devolve their decision on the pediatrician, giving up their self-determination. For other parents, social influences might play a central role when they do not believe to be competent in making the decision themselves, with some parents opting for a culturally embedded decision or for what has been previously done within the broader family (de Visser, Waites, Parikh, & Lawrie, 2011). However, our findings add that parents with a low perceived competence might nevertheless opt for an autonomous decision. In this case, we found that some parents had a preference for a gut-driven choice and that this, in turn, could be influenced by feelings of fear and anticipated regret derived from attendance of anti-vaccination meetings. Perceived competence and self-determination appear then to be unrelated. In some cases parental decision will lack both the self-determination which characterizes an autonomous choice and the perception of being competent to make an informed decision, two characteristics currently advocated by vaccination policies. In other cases, the perception of being unable to make a decision does not constitute an obstacle to parents' self-determination, who might follow their own

instinct and make an autonomous decision, running the risk of being at the mercy of anti-vaccination supporters or old-fashioned and unsafe beliefs. This might have serious implications for the formation of beliefs on the safety of the MMR vaccination, since most anti-vaccination narratives include, for instance, stories of children who allegedly became autistic after receiving the MMR jab (Betsch et al., 2011; Haase & Betsch, 2012).

Regarding importance (or meaningfulness) and impact, two sub-dimensions of psychological empowerment, it appears in the results that the MMR vaccination decision is listed by all parents among the most important decisions made for their child, including parents who have a negative attitude towards the MMR vaccination, who mainly worry about the vaccine's side effects on the child. This is in line with previous studies (Angelillo et al., 1999; Thorpe et al., 2012). However, while importance comes as an obvious component of the decision, independently of the attitude towards the vaccination, this theme is enriched by the finding that parents' concerns address three main levels which the MMR vaccination decision can have an impact on, namely the child's life, the family life-style, and the community/society. Commitment to preserve one's child and other children from the disease was found to be a predictor of parental vaccination decision (Brown et al., 2011), as well as parental concerns about a vaccination decision affecting family life-style (Gazmararian et al., 2010), and these issues are mainly cited by pro-vaccination parents. For some parents, importance was conceived in terms of contingency and stress, in the sense that the MMR vaccination decision was deemed less important than other choices since it did not require long and constant organizational efforts. In their quest for vaccination literacy and psychological empowerment, most parents seem to find a potential and desired ally in the pediatrician. Parents' expressed a need for shared vaccination decision-making with the child's healthcare provider, and this is in line with previous studies that reported discussion with a doctor was associated with receipt of the vaccination (Allison et al., 2010; McMurray et al., 2004). Ideally, shared decision making (SDM) in the context of childhood vaccination decision would be characterized by the pediatrician explaining the risks and benefits of the vaccination according to the individuals' competences, listening to parents' preferences, and discussing the decision with both parents so that the decision is informed and made in accordance with parental

values and needs (Taylor et al., 1997). Parents mainly advocated more discussion with the pediatrician prior to making the final decision as a way to be more involved and, thus, build their path towards a self-determined choice. Also, they asked to receive quality and tailored information on the risks and benefits of the vaccination according to their skills, which will lead to a perceived competent choice. Finally, they want the pediatrician to provide factual and procedural information, and tools to find, access, and understand this information, which is in line with what vaccination literacy would entail. Many parents felt that they could make an empowered decision, but that this did not mean being entirely independent and without the pediatrician's advice. Rather, they felt the need for an expert guide to better understand the risks and benefits of the vaccination, in order to make a choice that could ultimately be driven by themselves. This partly contradicts Opel's and colleagues' (Opel et al., 2013) finding that pediatrician's communicative style (presumptive vs. participatory) was related to vaccination receipt, in the sense that a presumptive approach was found to be correlated with higher compliance. This difference can be explained by cultural differences, as Opel's study was conducted in the US. A similar study should be conducted in Switzerland to assess whether parental needs for shared decision-making are in accordance with preference for a presumptive or participatory style by the pediatrician.

Limitations of the current study include that parents who accepted to participate in the study were most receptive to the topic of childhood vaccinations and more prone to discuss their experience and position. Due to the qualitative nature of the present study and its limited sample size, it should also be stressed that our findings cannot be generalized to the whole population. Moreover, social desirability bias should be taken into account, since participants might be more prone to present themselves as compliant with official recommendation, especially when they mentioned that adherence to the vaccination schedule for their older children was meant to secure immunity within their community. Furthermore, since the Italian-speaking part of Switzerland has a higher MMR vaccination coverage compared to the rest of the country (Richard & Masserey, 2009), exploring the concepts of vaccination literacy and empowerment in a low coverage area might have yielded different insights. However, our diverse recruiting system helped

us minimize these limitations ensuring a diversified sample in terms of country of origin and life-styles. Parents with an immigration background represented a large percentage of our sample. However, this is in line with current statistics on the migrant population in Switzerland. Moreover, as qualitative research is context-bound, parental reports are to be interpreted according to the Swiss context and healthcare system that immigrants necessarily navigate and integrate with their past beliefs. Qualitative research may represent an effective tool to understand health practices at the local level.

Our study stresses the importance of vaccination literacy and empowerment in the MMR vaccination decision making and, most importantly, of pediatricians as both literacy and empowerment providers during such a decision. First, if parents are given permission to participate in the decision, then the matter to be decided (vaccinating or not) appears to them to be unimportant - this seems to be an important and so far undiscovered and unwanted side effect of psychological empowerment. Second, the participants seem to be quite aware of their low competence in deciding about vaccination. If parents do not feel that they have the knowledge and the skills (in other words, the literacy) required to make a decision on their own, they will delegate other stake-holders to determine their choice, giving up their self-determination and, worse, running the risk of devolving the decision to antivaccination actors. Third, parents also seem to be quite aware of the tension between low literacy and high empowerment, mainly because they wish for more participation of pediatricians. This points to the interesting part that people share some understanding of the central premise of the health empowerment model: namely that high empowerment not accompanied by a high literacy is a dangerous thing.

### **3.5 Conclusions**

Our results yield a number of implications at multiple levels. A first level is more concerned with the medical encounter between parents and pediatrician, where the vaccination issue is addressed and discussed. Building on the needs that parents articulated in this study, there are a number of practical implications for pediatricians. Pediatricians should involve both parents in the decision-making, providing the proper information, motivating them to be active actors in this choice, and highlighting the importance of

parental role in managing their children's health as a way to reach empowerment. However, attention should be paid to their communicative style during vaccination recommendation (Opel et al., 2013). They should also stress that the importance of their decision lies in the non-compulsoriness of the vaccination, a policy that can be justified neither by a low risk of measles nor by a high risk of experiencing MMR-related side effects, but which is aimed at increasing their sense of responsibility and empowerment. Strategies to empower parents might include discussing the impact of the decision at the child, family and collective level, highlighting possible negative consequences of non-immunization. Concerning vaccination literacy in the specific, pediatricians are urged to provide clear, concise and tailored information regarding the risks and benefits of the MMR vaccination in a format that parents can understand and process. They should be able to counter-argue inaccurate arguments regarding the risks posed by the vaccination and those posed by the diseases that the vaccination aims at preventing, highlighting the disadvantages of missed or late pediatric immunizations. Lastly, they should be prompt in directing parents to reliable, accessible and clear information sources, before they fall victim of inaccurate information disseminated by anti-vaccination advocates, which is usually preferred for its narrative style. However, it should be stressed that following these recommendations may represent a challenging task for pediatricians, as being more actively engaged would inevitably require more work time – a limited resource.

Further implications of our results rest at a policy and institutional level. Policy-makers are urged to explicitly disclose the rationale behind the non-compulsoriness of pediatric vaccinations. This could be done by stressing the democratic and ethical character of the country's health related policies, or the thrust to positively engage parents and make them responsible for their children's health.

At a research level, further exploratory or conclusive research is needed to better understand the extent to which being literate and empowered contribute to the MMR vaccination decision-making. In particular, psychological empowerment deserves a deeper investigation in a population where vaccination rates are low, and measurement issues should be addressed to provide tools to quantitatively assess parental empowerment in making a MMR vaccination decision for their children.

Since parents are expected to make an informed and autonomous decision regarding their children's immunization, successful communication with respect to childhood vaccinations, and the MMR vaccination in particular, should take into account both issues of vaccination literacy and psychological empowerment. Healthcare providers and health authorities should promote parental empowerment as a process through which parents gain control and responsibility over the health decisions they make for their children, especially with regards to their immunization schedule. This could be done by highlighting the significance and the potential impact of the decision, and the importance of being literate on the topic to feel competent and autonomous. Efforts should be made, on the one hand, to give parents the proper information about the vaccination and the target disease(s), but also the skills to find more information, to assess its reliability and, ultimately, to understand it. This can in turn increase parents' perception of being competent and thus make an empowered decision.

## Chapter IV

What are parents' perspectives on psychological empowerment in the  
MMR vaccination decision? A focus group study

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*Abstract*

**Objectives:** Most developed countries do not have compulsory immunisation requirements, but instead issue recommendations. Although parents are expected to make an informed, autonomous (i.e., empowered) decision regarding their children's vaccinations, there is no evidence about how parents' interpret this demand nor on the latitude of their decision-making. The goal of this study is to gain insights from parents residing in a low measles-mumps-rubella (MMR) uptake area on what constitutes feelings of empowerment in the decision they have to make on their child's MMR vaccination.

**Design:** A qualitative study employing focus group interviews.

**Setting:** 11 vaccination centers and hospitals in the Province of Trento, Italy.

**Participants:** 24 mothers and 4 fathers of children for whom the MMR vaccination decision was still pending participated in 6 focus groups.

**Results:** Autonomy and competence were salient themes in relation to empowerment, and were further connected with beliefs regarding legal responsibility and ethics of freedom concerning the decision, parents' relationship with the pediatrician (trust), feelings of relevance of the decision and related stress, and seeking, avoidance, or fear of vaccination-related information. Competence was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent.

**Conclusions:** Since parents' interpretation of empowerment goes beyond mere perceptions of being informed and autonomous and differs across individuals, it is important that this construct be correctly interpreted and implemented by best practice, for instance by explicitly adopting a relational conception of autonomy. Knowing whether parents want to make an empowered decision and what their information and autonomy needs are might help health professionals adapt their communication about immunisation, and promote parental perception of making an informed, autonomous decision.



## **4.1 Introduction**

The call for patient empowerment and patient-centered care that is pervading in almost all health contexts has also involved parents as decision makers on behalf of their children. The prominent principle of preserving and promoting individuals' autonomous choices and actions has been translated, in the immunisation context, into the principle of protecting and promoting parents' ability to make and act on free, informed decisions, resulting from 'capable and uninfluenced deliberation' (Kukla, 2005). With ethical attention being increasingly drawn to the vaccination decision, current vaccination programmes in most developed countries have now called for parents' willingness to make an intentional, informed and autonomous decision. This is transferred, for practical purposes, into the widespread use of informed consent forms disclosing the risks as well as the benefits of the immunisation (Woolley, 1977) and the policy to make or keep vaccination non-compulsory (El Amin, Parra, Kim-Farley, & Fielding, 2012; Haverkate et al., 2012). Thus, public health authorities tacitly interpret empowerment as an ethically justified process that follows the acknowledgment of the official recommendations and eventually leads to a decision that is both free from controlling influences and not mandated by law. However, there is little concern with understanding how to practically recognize, safeguard and promote empowerment in the vaccination decision, beyond the mere use of informed consent and non-mandatory immunisations.<sup>1</sup> How parents have interpreted and to what extent they have adopted the demands put on them when choosing whether or not to vaccinate their children has only been explored marginally (Fadda, Depping, et al., 2015). Furthermore, while several predictors are known (Favin, Steinglass, Fields, Banerjee, & Sawhney, 2012), such as risk perception (Bennett & Smith, 1992; Betsch & Wicker, 2012; Bond et al., 1998; Spier, 2001; Tarrant & Thomson, 2008), beliefs and attitudes (Brown et al., 2011; Gilkey et al., 2014; Heininger, 2006; Lavail & Kennedy, 2013; Yaqub et al., 2014), safety concerns (Andreae et al., 2004; Bardenheier, Yusuf, Schwartz, et al., 2004; Streefland, 2001), trust (Austin et al., 2014; Cooper et al., 2008; Larson, Leask, et al., 2013; Larson, Smith, et al., 2013; Larson et al., 2014; Mills et al., 2005; Tarrant & Thomson, 2008) and social norms (Oraby et al., 2014), parents' perceptions about their empowerment in the vaccination decision have so far been almost

exclusively neglected as possible drivers of their vaccination behavior, despite previous work suggesting the relevance of empowerment-related dimensions such as self-efficacy and self-determination in this health decision (Fadda, Depping, et al., 2015).

#### *4.1.1 Psychological empowerment*

Although being recognized as a key element in the current shift towards patient-centered healthcare, there is little agreement on what constitutes psychological empowerment (The Lancet, 2012). Empowerment received increasing attention during the 1980s, when it was applied to the health context. Zimmerman (Zimmerman, 1995) proposes a definition of psychological empowerment as a construct that consists of three inter-related dimensions: (1) an intrapersonal dimension consisting of cognitive appraisals of control, competence, motivation and self-esteem; (2) an interactional dimension consisting of critical skills and knowledge; and (3) a behavioral dimension reflecting participatory, change-oriented behaviors in formal and informal contexts and organizations.

Spreitzer (Spreitzer, 1995, 1996), on the other hand, sees psychological empowerment as an intrinsic motivational construct of the individual and separates Zimmerman's concept of intrapersonal empowerment into four dimensions or cognitions: (1) meaningfulness (the extent to which what one does is perceived as being important), (2) competence (one's perceived competence to carry out an action), (3) impact (the perception of making a difference through a certain action) and (4) self-determination (the extent to which what we do is perceived as autonomous).

In the context of health, empowerment has been found to be related to positive health outcomes (Florian & Elad, 1998), more active decision-making (Davison & Degner, 1997), increased knowledge (Mishra et al., 1998), better self-management (Tsay & Hung, 2004) and more satisfaction with one's decision (Davison & Degner, 1997).

#### *4.1.2 Aim of the study*

Psychological empowerment may vary greatly across individuals and contexts, and fluctuate over time (Cornell Empowerment Group, 1989). A single definition and measure cannot therefore be generalized to multiple settings (Akey, Marquis, & Ross, 2000). The

aim of the current study is to explore parents' perspectives on empowerment in the context of the measles-mumps-rubella (MMR) vaccination decision in a low MMR covered area, building on similar previous work (Fadda, Depping, et al., 2015) and grounding in the conceptualization of psychological empowerment as a set of four subdimensions proposed by Spreitzer (Spreitzer, 1995, 1996): (1) meaningfulness, referring to the degree to which an individual thinks that making a vaccination decision regarding his or her child is an important issue; (2) competence, referring to the degree to which an individual feels able to make a sound vaccination decision; (3) impact, referring to the degree to which an individual feels that making a decision over the vaccination can generate a number of outcomes; (4) self-determination or autonomy, referring to the degree to which individuals think that their vaccination decision is free from controlling influences. For this purpose, we decided to conduct qualitative focus groups to maximize parents' discussion, since we considered the vaccination decision as a socially constructed experience based on interactions with other individuals (Nassar-McMillan, Wyer, Oliver-Hoyo, & Ryder-Burge, 2010). The decision-making process focus of the present study is specific to the context of the MMR vaccination decision due to a number of features that make this vaccination unique compared with other childhood vaccinations. Not only is MMR at the center of the autism controversy (Maisonneuve & Floret, 2012) but also, since it is made of live attenuated viruses, administering this vaccine might be seen by parents as the closest thing to causing a natural infection (CDC, 2015b). Furthermore, MMR coverage is decreasing in several developed countries and postponing this vaccination may have serious consequences for future outbreaks (Dannetun et al., 2004).

## **4.2 Methods**

### *4.2.1 Recruitment*

We recruited our focus group participants through the 11 vaccination centres of the Province of Trento, Italy. MMR coverage in this area is 84.21% despite the 95% required threshold to achieve herd immunity (Italian Ministry of Health, 2015), making it one of the seven regions in Italy where more than 15% of children have not been vaccinated with the first dose of MMR by the age of 2 years. To be included in the study, parents had to

have at least one child aged less than 1 year or for whom an MMR vaccination decision was still pending, and be residing in Italy. Italy's MMR vaccination schedule envisages two doses, which are given when the child is 12–15 months and 5–6 years old, respectively (Italian Ministry of Health, 2016). In the Province of Trento, childhood vaccinations are administered in the public health and vaccination centers located in each of the 11 local areas that the Province is divided into. Parents are invited to the vaccination through a written letter; in case of no-show for the scheduled appointment, parents are sent two more letters of solicitation. Vaccinations are usually administered by trained nurses and health professionals who are supervised by a preventive medicine doctor in the vaccination centers.

Parents were handed an invitation to the study by the nurses during their vaccination appointment for the first or second dose of the diphtheria, tetanus and pertussis (DTaP) vaccination, which are administered when the child is aged 3 and 5 months, respectively. Diphtheria and tetanus vaccinations are mandatory in Italy (parents refusing it for their children may be subject to a fine). The invitation stated the objectives of the study, the interview process and a guarantee of confidentiality. Parents filled out the invitation with their contact details and returned it in a box placed in the waiting room. Invitations were collected and we contacted each participant either by phone or by email, to arrange the focus group meetings.

#### *4.2.2 Data collection*

Focus groups were held in a private setting within the local health authority buildings between March and May 2015. Each focus group lasted 1 h and one/two facilitators and one recorder were present. Participants sat in a circle in order to promote discussion. Before starting the interview, we obtained consent from the participants and informed them about the scope of the study, its duration, the right to withdraw from the study at any point and the reward that would be offered to them at the end of the focus group. After the interview, we asked the parents to fill out a brief survey with questions on vaccination knowledge (Zingg & Siegrist, 2012) and sociodemographic variables relative to both

parents (origin, age, education, number and age of children) and gave them a skin care product for their child together with a debriefing letter.

A list of semistructured questions aimed at probing parents on meanings and interpretations associated with empowerment in the MMR vaccination decision was developed by the research team on the basis of the literature on psychological empowerment, on Spreitzer's empowerment model and on previous health-related empowerment scales (Bennett & Smith, 1992; Bond et al., 1998; see Appendix 5). Questions were open-ended and broad in order to understand parents' decision-making processes as well as their experiences and feelings. We kept the grid as flexible as possible to allow a free-flowing discussion.

We recorded each interview, using a digital voice recorder, and transcribed them verbatim. We reached saturation of the data at six focus groups, when we decided that additional interviews would not yield new data, but only confirm what had already been found (Guest, 2006).

#### *4.2.3 Data analysis*

To guarantee the quality of the findings and to generate as many insights as possible, which would be merged or further distinguished at a later stage, two coders (MF and EG) independently performed an inductive thematic analysis (Braun & Clarke, 2006) of the transcripts. We proceeded according to the following stages: we initially read the transcripts several times to become familiar with the content, manually underlined meaningful quotes, gradually grouped them under a number of labels, organized all labels hierarchically and created links among labels to channel them into broader themes. To validate the results, comparisons between the two coders took place in-between each of the aforementioned stages, so that the preliminary themes, labels and quotations were constantly discussed, and interpretation discordances resolved through dialogue and by constantly referring to the transcripts. All themes were then compared with Spreitzer's empowerment conceptualization into four subdimensions (Spreitzer, 1995, 1996) to check for correspondences. Both the transcription and the analysis of the interviews were conducted in the original language (Italian).

### **4.3 Results**

#### *4.3.1 Characteristics of the sample*

We sent 1000 invitations to the 11 vaccination centers, distributing the number according to their size. Of the total amount of invitations that were sent, we received 128 invitation forms completed with the participant's details. Eligibility of the recruited parents was checked by the vaccination center nurses; therefore, the invitation form was only handed to eligible participants. We contacted all 128 parents, of whom 67 were available to participate in the focus groups. Finally, 28 parents (dropout rate 58%) took part in six focus groups, each including four to six participants. All participants filled out a paper-and-pencil survey on vaccination knowledge and sociodemographic variables. Most participants were mothers (86%) and had Italian nationality (82%). The high share of non-Italians (against 8.3% immigrants living in Italy; Italian National Institute of Statistics, 2016), ensured diversity in terms of origin in our sample. The average age was 36.5 years (SD=5.5; range=28–48), while in terms of education about half of the sample had completed university (46%), approximately half had completed secondary education (46%) and only two participants either had frequented a professional school or did not continue studying after obligatory school. Most parents (64%) had more than one child, meaning that they had made an MMR vaccination decision for at least one older child. Vaccination knowledge was found to be on average 6.15 (SD=2.06; range=0–9), where 9 was the highest possible score. See Table 2 for an overview of participants' characteristics.

**Table 2.**  
*Characteristics of the participants*

	(N = 28)
Sex	
Women	<i>n</i> = 24 (86%)
Men	<i>n</i> = 4 (14%)
Age	M = 36.5; SD = 5.5; range = 28-48
Origin	
Italy	<i>n</i> = 23 (82%)
Other EU	<i>n</i> = 3 (11%)
Other non-EU	<i>n</i> = 2 (7%)
Education	
University	<i>n</i> = 13 (46%)
Professional school	<i>n</i> = 1 (4%)
Secondary school	<i>n</i> = 13 (46%)
Obligatory school	<i>n</i> = 1 (4%)
Number of children	
1 child	<i>n</i> = 10 (36%)
2-5 children	<i>n</i> = 18 (64%)
Children's age	
<6 months	<i>n</i> = 2 (7%)
<12 months	<i>n</i> = 25 (89%)
>2 years	<i>n</i> = 1 (4%)
Vaccination knowledge	M = 6.15; SD = 2.06; range = 0-9
Attitude towards the MMR vaccination	
Undecided	<i>n</i> = 9 (32%)
In favor	<i>n</i> = 19 (68%)

#### 4.3.2 Issues of empowerment

In general, parents held varying views about empowerment in relation to the MMR vaccination decision, with most participants affirming that their views apply to all pediatric vaccinations and are not restricted to the MMR immunization. When asked about their reasons for participation, most parents reported that they hoped to find answers to their questions about childhood vaccinations, to understand why some parents do not want to vaccinate, to meet other parents to discuss the topic and know what they think, and because they considered providing information and helping research a civic duty. The majority of the participants found that vaccination was a public good, and thus deserves discussion and meetings.

Generally, about one-quarter of the parents reported they felt uncomfortable in making the MMR vaccination decision due to safety concerns, uncertainty and low perceived competence, while the large majority reported to be confident with their choice. Autonomy was related to competence, which was interpreted as medical knowledge and information-seeking skills, but it was also related to the extent parents perceived the pediatrician to be competent and to the quality of their relationship with the pediatrician. Parents held varying beliefs regarding the legal responsibility (the possibility to be held responsible in case of vaccination-related or disease-related adverse events) and freedom of the decision, diverse feelings of relevance of the decision and related stress, as well as different orientations towards vaccination-related information.

#### 4.3.3 Competence as a key to autonomy

The majority of the participants reported that, to feel autonomous in the MMR vaccination decision, it is crucial to possess adequate competence. Competence was interpreted as medical knowledge as well as a set of skills related to finding, objectively assessing and finally understanding vaccination-related information:

*“[Autonomy means] gathering information, not letting myself being influenced by other mothers. I got information at the prenatal classes, where there was a pediatrician. Then I asked my own pediatrician. Then those from the vaccination*



*center came in. [...] Autonomy in this sense, I documented myself". (Mother, 32, Italian)*

*"You look at different websites, different forums and different arguments. What really needs to be looked at. [...] Then you have to be objective, you have to step out of the thing, say, and try to analyze what you've just read. Rationally". (Mother, 28, Italian)*

Very few participants, however, stressed that it is impossible to reach complete autonomy because parents can never have the appropriate skills to make a decision by themselves, but always need to rely on medical professionals.

*"I think it's impossible to be autonomous for us, as parents, if we are not doctors. We do not have the skills to make such a decision. It's far better to rely on someone who does that as a job, who can explain to you the pros and cons, the reasons...Then you, as a parent, can make your own decision, but then it's your own personal decision which is not based on the scientific method". (Mother, 48, Italian)*

The large majority of parents reported feeling competent and, consequently, autonomous, when they could also obtain vaccination-related information and guidance from an expert whom they could trust, for example, the child's pediatrician.

*"[I feel competent]...when I have a consultation with someone competent that I can trust". (Mother, 31, Italian)*

*"[To feel autonomous] I completely rely on the pediatrician. She is also the one who cared for me until I was 14, so I really trust her. If I notice that she is calm, I also get calmer". (Mother, 28, Italian)*

In this context, about half of the participants reported that they tended to decide what the pediatrician suggested if they perceived there was affinity between them in terms of opinion.

*“I’m afraid that...I would chose the opinion that is closer to mine, ‘cause in the end one already has an opinion...I think I would go for...I would not be able to be completely objective ‘cause in the end you feel fully in tune with someone if that idea appeals to you most”. (Mother, 38, Italian)*

Parents also listed a number of characteristics the ideal pediatrician should possess to be considered competent and trustworthy, and to establish a good relationship, namely availability, empathy, interest and attentiveness. Few participants complained that their pediatricians lacked these skills and that, as a result, they had a poor relationship with them.

*“When he dedicates me time, when I understand he is listening to me and is answering exactly what I am asking”. (Mother, 30, Italian)*

#### 4.3.4 Autonomy as legal responsibility and freedom

When asked about their interpretation of autonomy in the MMR vaccination decision, the majority of the participants reported that having a free choice on their child’s immunization was equivalent to being asked to assume the responsibility for any potential positive or negative consequences that might result from vaccinating or not vaccinating their child. Parents differed in their views on this theme, with the majority reporting that they felt being appointed as a role not belonging to them. These participants considered that making the final decision on the vaccination was a matter of legal responsibility, which parents should not assume since they lack the medical skills needed to make an informed decision. Referring again to competence as being vital to autonomy, they reported that their medical understanding was inadequate to enable an autonomous, responsible choice.

*“For me autonomy means responsibility, and you are not always as informed or as prepared as a doctor would be, so...well, you can have the freedom to choose yes or not, but...I don’t always feel up to the situation”. (Mother, 38, Italian)*

Only a few participants reported that they were willing to assume full responsibility for the decision, even in case of negative consequences due to the vaccination or the disease.

*“You cannot blame yourself for everything, but you have to take on your responsibilities”. (Mother, 40, Italian)*

Almost all parents also reported that being autonomous in the vaccination decision is a matter of freedom. Parents had opposite views on this theme, with half of them seeing autonomy as a dangerous right that parents should not have. This group of participants included those who were not willing to assume the legal responsibility of their MMR vaccination decision.

*“I do not find this autonomy fair. I noticed that several diseases spreading around in the schools could easily be prevented by vaccinating. In my opinion, those should be obligatory. After all, I cannot decide by myself”. (Mother, 31, Italian)*

The other half of the parents, while stressing the ethical aspects of being free in the vaccination decision, reported that it is morally important that all parents are free to make the final decision on their child’s MMR vaccination.

*“The free choice on everything seems fair to me. It is reasonable to me that nothing is compulsory any longer. However, if this free choice means that, out of 100 children, 60 to 70 vaccinate and 30 do not, then we should re-evaluate the situation”. (Mother, 48, Italian)*

#### 4.3.5 Information orientation

The majority of parents reported that being autonomous in the MMR vaccination is a matter of actively looking for information, expecting the information to be delivered by the pediatrician or the health authorities, or simply avoiding any information. Half of the participants described themselves as active information seekers who try to consult as many sources as possible, stating that it is up to parents to look for information themselves.

*“If one wants information, he or she should get out and find it”. (Mother, 46, Italian)*

About a quarter of the participants, rather, expected the health authorities, medical professionals and vaccination centers to provide them with easy and accessible information prior to their appointment for the vaccination, stating that it is not up to parents to look for vaccination-related information.

*“It’s up to the pediatrician to start by providing information. They take it for granted that we know all the things, but instead... this is not always the case”. (Mother, 30, Non-EU)*

In this context, about a quarter of the participants reported that fear of the information that could be found (possible side effects of the MMR vaccination, including autism) and lack of medical knowledge prevented them from looking for information on vaccinations and led them to avoid the information given by other parents.

*“I tend to stay away from the websites ‘cause you read all sorts of things. It happened to me once, then I worried and started to do, to think much worse than it was, so I don’t even go and look at it!”. (Mother, 42, Italian)*

#### 4.3.6 Relevance of the decision and related stress

For the majority of the participants, confidence in the MMR vaccination decision-making was related to the relative importance of this decision. Almost all parents reported that the vaccination decision is something you just make, it is not among the priorities and does not cause stress.

*“For me it’s among the last ones. Partly because I had health issues...and then because it was a decision that I had already made, in the sense that I knew I just had to do it, so that was not such a hard decision”. (Mother, 30, Other EU)*

A small minority reported that making the decision is among the most important decisions, as it becomes a stressful task that consumes time and energy, and creates tensions in the couple. These parents also reported to have a poor relationship with their child’s pediatrician.

*“Deciding for MMR has really been a moment of tension between me and my husband...I remember. It was not like deciding whether to breastfeed or not. That was my decision. We really went through a period of tension”. (Mother, 38, Italian)*

## 4.4 Discussion

### 4.4.1 Main findings

The aim of this focus group study was to explore the construct of psychological empowerment in the MMR vaccination decision among a sample of parents residing in a low MMR coverage area in Italy. Issues of autonomy and competence largely dominate our results, and appear to be strictly inter-related. Autonomy, interpreted as both responsibility and freedom, seems to largely depend on parents’ competence and this, in turn, on their relationship with the child’s healthcare provider, the relevance of investing in the decision and their information-seeking behaviors.

First, the large majority of the participants reported they could feel competent and autonomous not only when having the appropriate knowledge and information-seeking skills but also when they could rely on a competent and trustworthy pediatrician. Other studies found that trust in the pediatrician can be a relatively important factor influencing parents' vaccination decision (Gust et al., 2008; Jackson, Cheater, & Reid, 2008; McMurray et al., 2004) and, considering that according to the Italian system children are administered the vaccine by a nurse in a vaccination center and not by their pediatrician, it should be further explored whether trust in the vaccine provider as well could compensate for parents' perceived lack of competence. Few parents also stated they would rather listen to a pediatrician with vaccination opinions similar to theirs. These findings confirm a large set of literature on the importance of the child's provider on parents' vaccination decision (Austvoll-Dahlgren & Helseth, 2010; Kennedy et al., 2011; Kennedy, Lavail, Nowak, Basket, & Landry, 2011; Opel et al., 2013; Taylor et al., 1997) and on the tendency many parents have to choose a provider with vaccine beliefs similar to their own (Mergler et al., 2013). The results are also in line with the theory of relational or conscientious autonomy, which assumes that our sense of autonomy depends on other individuals' influence on our lives (Entwistle, Carter, Cribb, & McCaffery, 2010). The theory stresses that "social interactions can affect autonomy not only by influencing individuals' health-related preferences and choices but also their self-identities, self-evaluations, and capabilities for autonomy" (Entwistle et al., 2010). Our findings suggest that parents might report that they can never be in a position to make decisions autonomously because their healthcare provider will always know more than they do. However, they can at the same time be compliant with the pediatrician's recommendation, but claim the decision as their own anyway since it was guided by a trusted source with whom they have a good relationship (Kukla, 2005). The theory has also been confirmed by other studies (Mendick, Young, Holcombe, & Salmon, 2010), which found that patients felt they 'owned' their decision when it was the one recommended by a trusted medical professional. Thus, to feel empowered does not necessarily mean that parents will always make decisions on their own. Having the ability to negotiate the extent to which one is involved in decision-making is key; in some instances, parents will be entirely guided by

health professionals, in other situations it is a genuinely shared decision, and in yet others, entirely the decision of the parent. It is a wholly context-specific decision (Jackson et al., 2008).

Second, the vast majority of the participants found that autonomy was related to issues of responsibility and freedom, thus reinforcing the idea that autonomy is connected to ‘morality, personhood and agency’ (Kukla, 2005). While only a small, educated minority was willing to assume the legal responsibility derived from making an autonomous choice, participants were equally split in their opinion regarding the morality of having the freedom to make the final decision. Previous studies found that adolescents’ perspectives on their legal responsibility in relation to their vaccination might be a barrier to immunization adherence (Ford, English, Davenport, & Stinnett, 2009). With respect to freedom of choice, studies also found that a small proportion of individuals are unlikely to vaccinate when immunizations are compulsory (Seale, Leask, & Macintyre, 2009; Kennedy et al., 2005).

A third major finding was that parents reported about their preferences regarding their vaccination-related information when asked about their understanding of autonomy and competence in the MMR vaccination decision. Participants distinguished themselves as active seekers, passive recipients or information avoiders. It is worth noting that most information avoiders and passive seekers also had lower educational levels. Research has previously found that those with more access to health-related information and better information-seeking skills are more likely to make informed medical decisions (Viswanath & Finnegan, 1996), and that information-seeking preferences can affect one’s vaccination decision (Gust et al., 2008). Moreover, information orientation (engagement vs apprehension) has been found to predict one’s objective and perceived ability to use information technology for health (Strekalova, 2014).

A last finding relates to the empowerment subdimension of meaningfulness. When asked to compare the MMR vaccination decision to other decisions made for their child, the majority of the participants reported that it is something natural ‘you just do’, something that neither causes stress nor requires energy. These parents also reported that their MMR vaccination decision could have an impact not only on the health of their child

but also on their community's health. A small minority, on the other hand, reported that deciding over MMR was a time-consuming, stressful task, which topped all other decisions. It is worth noting that these parents also lamented a poor relationship with the pediatrician. The idea that vaccination might be an obvious choice and a normal part of bringing up a child, and that it might require more or less thinking on the basis of its relative relevance, was also found in previous studies (Austvoll-Dahlgren & Helseth, 2010; Fadda, Depping, et al., 2015; Gust et al., 2008).

#### *4.4.2 Strengths and weaknesses of the study*

This is the first study to shed light on parents' understanding of empowerment in their MMR vaccination decision-making in a low MMR coverage area. Previous work has explored the construct of psychological empowerment in the MMR vaccination decision (Fadda et al., 2015a), suggesting the relevance of parental self-efficacy and self-determination in such a decisional context. The study is subject to a number of limitations. First, the self-selected nature of our sample might have resulted in focus group participants mainly being provaccination parents willing to share their compliance with the official immunization recommendations. Second, recruiting through the vaccination centers might have prevented us from reaching those who are highly opposed to immunizations and who even refuse the DTaP vaccination. However, this could also be seen as a strength of the study, as a large number of our participants were not completely decided on whether to vaccinate or not. Third, due to a high dropout rate, the focus groups conducted in this study included only four to six participants each. While groups of six participants are generally the minimal recommended number in focus groups, discussion among the participants was not prevented by the limited sample size thanks to participants' diversity in their opinion. Furthermore, the research team that participated in the focus group was limited to two members (one facilitator and one recorder) when the size of the focus group was below six participants. Finally, since we extracted our results from qualitative reports of a small sample of parents, our findings cannot be generalized to a bigger population.



#### *4.4.3 Implications*

The findings have a number of implications both for theory and for practice. First, the construct of empowerment appears to be perceived by parents in the context of the MMR vaccination decision as more nuanced than our initial conceptualization. While autonomy and competence are perceived as salient dimensions of the construct, they are strictly related to issues of freedom, responsibility, trust in the pediatrician, relevance of the decision and information orientation.

In terms of practice, it is worth noting that the large majority of participants reported as not making distinctions between vaccinations; therefore, our findings could be applied to multiple vaccinations. Since empowerment was viewed in different ways by our participants, ambiguous or extreme interpretations of the empowerment principles (such as autonomy) need to be avoided for all vaccinations as they might result in contract-like relationships between parents and health professionals, isolate parents with their responsibility of the decision, or curtail other possible immunization solutions (Ells, Hunt, & Chambers-Evans, 2011). Also, it should be noted that not all parents wish to be empowered in the same way. Some might need to be guided by the child's pediatrician to feel in control of their decision, by simply conforming to his/her advice or the official recommendations and avoiding any other information sources. Others might highly value active information, seeking to feel competent, and finally make an autonomous decision. In all instances, as other studies found (Gust et al., 2008; Jackson et al., 2008; Leask et al., 2012), it should be recognized that pediatricians are key in parents' empowerment in the vaccination decision. Not only do they need to be perceived as competent professionals by parents, but they also have to build a trustworthy relationship with them (Gust et al., 2008). Furthermore, they should be willing to address parents' questions and concerns, make an effort to understand whether parents do or do not wish to share in the decision-making, recognize how their interactions and relationships with parents can either enable or impair parents' empowerment, and finally adapt their communication style accordingly (Gust et al., 2008; Jackson et al., 2008; Leask et al., 2012).

#### *4.4.4 Future research*

Since a particular vaccination decision, the acceptance of the informed consent, or the attitude driving a given vaccination behavior, may or may not be an expression of parental empowerment (Kukla, 2005), future quantitative research has to clarify whether empowerment and its subdimensions can have an impact on the acceptance of vaccination recommendations. In this sense, developing appropriate measures of the empowerment construct in this particular context, and testing its relationship with other key variables such as vaccination knowledge and risk perception, would be a valuable step.

### **4.5 Conclusions**

Parents' empowerment in the vaccination decision should be encouraged to serve parents' rather than institutional interests (Salmon & Hall, 2004). Misconceived assumptions about empowerment might be a contributing factor to vaccine hesitancy and to health professionals' frustration about their potential to effectively cooperate with parents (Ells et al., 2011). If parents are asked to be empowered in the vaccination decision, it is important that this be correctly interpreted and implemented by best practice. In this sense, by overtly employing relational autonomy as a crucial element of the vaccination decision, empowerment in parental immunization choice might become a more comprehensible and stronger principle, and could help pediatricians and other health professionals to genuinely promote and implement parents' autonomy (Ells et al., 2011). Health professionals can appeal to a principle of parent empowerment by facilitating parents' ability to make an informed and autonomous decision and, at the same time, by promoting their relational autonomy (Ells et al., 2011). This can be carried out by ensuring that parents are sufficiently informed, have the skills to find, assess and understand vaccination-related information by other sources, and by building a trustworthy relationship with them. On the other hand, a view of empowerment that isolates parents in their decision-making would not be in line with a patient-centered/parent-centered model (Ells et al., 2011). Furthermore, health authorities' risk communication should include a description of the reasons for restricting and expanding

individual rights in a way to maximize comprehension, since there is evidence that informed consent does not always provide clear and useful information (Attena et al., 2014; Salmon & Omer, 2006). Trained staff (preventive medicine experts, vaccination nurses) should also be available in the vaccination center, to encourage parent's relational autonomy and to answer questions (Woolley, 1977).

The advocated principle of parental empowerment in the vaccination decision in a context of voluntary participation, while suggesting that parental autonomy is central, does not mean that it is absolute (Verweij & Dawson, 2004).

## Chapter V

### Validation of a scale to measure parental psychological empowerment in the vaccination decision

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*Abstract*

**Objective:** Parents' empowerment is advocated to promote and preserve an informed and autonomous decision regarding their children's immunization. The scope of this study is to develop and evaluate the psychometric properties of an instrument to measure parents' psychological empowerment in their children's vaccination decision and propose a context-specific definition of this construct.

**Methods:** Grounding in previous qualitative data, we generated an initial pool of items which was later content and face validated by a panel of experts. A pretest allowed us to reduce the initial pool to 9 items. Convergent and discriminant validity measures included the General Self-Efficacy Scale (GSES), a Psychological Empowerment Scale (PES), and the Control Preference Scale (CPS). Vaccination-related outcomes such as attitude and intention were also included.

**Results:** Principal Component Analysis (PCA) revealed a 2-factor structure, with each factor composed of 2 items. The first factor concerns the perceived influence of one's personal and family experience with vaccination, while the second factor represents the desire not to ask other parents about their experience with vaccination and their lack of interest in other parents' vaccination opinion.

**Conclusions:** In light of its association with positive immunization-related outcomes, public health efforts should be directed to reinforce parents' empowerment.

*Keywords*

Vaccination, decision-making, psychological empowerment, parents, scale development.

## 5.1 Introduction

With the emergence of a patient-centered healthcare model, most developed countries have started to pay increasing attention to the empowerment of patients as well as parents as decision-makers for their children's health (Jackson & Cooper, 1989; Jones, Winslow, Lee, Burns, & Zhang, 2011). The principle of promoting and preserving parents' involvement in the decisions and actions concerning their children has been applied to a number of pediatric health conditions such as prematurity, autism, obesity and disability (Gonya, Martin, McClead, Nelin, & Shepherd, 2014; Jones et al., 2011; Melnyk et al., 2004; van der Pal, Alpay, van Steenbrugge, & Detmar, 2013). Interventions aimed at promoting parents' empowerment were found to have positive effects both on parents' psychological outcomes and on the child's health (Gonya et al., 2014; Melnyk et al., 2004; van der Pal et al., 2013).

In the past few years, parent's empowerment in the immunization context has started to receive the same attention. Within the ubiquitous and unceasing debate about the safety and efficacy of vaccinations, an ethical discourse has emerged on compulsory vaccination, calling for parents' informed and self-determined immunization decisions. Public health authorities assume parents make an informed decision when they formally acknowledge the risks and benefits of the vaccination and its target disease(s) by signing a consent a form. The use of non-compulsory immunization is assumed to promote a self-determined parental choice. However, beyond the mere use of informed consent forms (Woolley, 1977) and the non-compulsoriness of vaccination (El Amin et al., 2012; Haverkate et al., 2012), it is so far unknown how parents have interpreted this call for empowerment. Furthermore, no research has been conducted so far to test whether psychological empowerment could be a predictor of parents' vaccination-related choices (Kukla, 2005).

### *5.1.1 Psychological empowerment*

Empowerment, which is often referred to as "psychological" when it applies to individuals rather than groups, has become a ubiquitous word (Woodall, South, & Warwick-Booth, 2010). Despite being often called for in the health domain as a strategy

to improve health-related outcomes, an agreed definition of empowerment is still missing as both practitioners and scholars have used it to mean different things in different settings. Rappaport defines empowerment as “a process by which people, organizations and communities gain mastery over their affairs” (Rappaport, 1987). In this sense, empowerment is viewed as a process by which people increase control over their lives and health, and can be applied to individuals or communities (Woodall et al., 2010). For our purposes, it will suffice to define psychological health empowerment as the belief and claim that it is within reach of a person to contribute substantially to protect and regain his or her own health.

Psychological empowerment is not a one-dimensional concept. According to Zimmerman, empowerment is both a process and an outcome whose attributes include perceived control, perceived competence, motivation, understanding of the socio-political environment, self-esteem and proactive behaviors (Zimmerman, 1995). Another popular list of the attributes of psychological empowerment comes from the organizational literature. Grounding in the definition proposed by Conger and Kanungo first (Conger & Kanungo, 1988), and refined by Thomas and Velthouse later (Thomas & Velthouse, 1990), Spreitzer (1995, 1996) sees psychological empowerment as “a motivational construct manifested in four cognitions: meaning, competence, self-determination and impact” (Spreitzer, 1995, 1996). The scholar adds that, taken together, these characteristics represent an active orientation to a work role, meaning that the individual aspires at shaping his role and environment, and feels competent in doing it (Spreitzer, 1995, 1996).

A large literature review that investigated the effectiveness of empowerment interventions found that empowerment strategies were “promising” in their capability to improve health-related outcomes (Wallerstein, 2006). Another review on the effectiveness of empowerment on health and wellbeing suggested 5 key areas to group all health-related outcomes that can benefit from empowerment interventions on the basis of the available literature: (1) improved self-efficacy and self-esteem, (2) greater sense of control, (3) increased knowledge and awareness, (4) behavior change, and (5) a greater sense of community, broadened social networks and social support (Davison &

Degner, 1997; Florian & Elad, 1998; Mishra et al., 1998; Tsay & Hung, 2004; Woodall et al., 2010).

More recently, research has called for further exploration of this construct in the context of the vaccination decision-making, based on the speculation that higher levels of empowerment, if connected with inaccurate information on the vaccination, might lead to vaccine hesitancy (Schulz & Nakamoto, 2013). Previous qualitative findings (Fadda, Galimberti, Carraro, & Schulz, 2016) indicate that, when making a decision for their children's immunization, parents interpret empowerment as a set of different characteristics. Feelings of control are strictly linked to the perception of being competent and free to choose whether to be guided by trusted professionals, and autonomy can be interpreted by taking responsibility of one's decisions and having the freedom to choose whether or not to vaccinate (Schulz & Nakamoto, 2013). However, no instrument is currently available to quantitatively assess whether these issues can be grouped under the same umbrella and become part of a single empowerment construct or its sub-dimensions. Furthermore, a meaningful definition of empowerment is needed in such a context.

Scholars agree that it can be misleading to apply a single definition and measure of psychological empowerment to different populations and settings (Akey et al., 2000; Zimmerman, 2000), as it might not appropriately reflect the uniqueness of different behavioral contexts (Cornell Empowerment Group, 1989). Furthermore, the literature on psychological empowerment mostly refers to the degree individuals perceive themselves to be competent and autonomous in their actions, rather than in their decisions (Akey et al., 2000).

### *5.1.2 Aim of the study*

The aim of the current study was to describe the development and evaluate the psychometric properties of a scale to measure parents' psychological empowerment in the context of the vaccination decision for their children. Furthermore, we aimed at adjusting the original definition of this construct so that it can adequately reflect this particular decisional context on the basis of our findings. To ensure consistency with previous work we conducted on psychological empowerment in the vaccination decision (Fadda,



Depping, et al., 2015; Fadda et al., 2016; Schulz & Nakamoto, 2013), the present study was partly grounded in the conceptualization of psychological empowerment as a set of four sub-dimensions proposed by Spreitzer (Spreitzer, 1995, 1996). These dimensions are (a) meaning, or the extent to which parents think that their vaccination decision is important; (b) competence, or the degree to which parents feel able to make a vaccination decision; (c) impact, or the extent to which parents perceive their vaccination decision as impactful; (d) self-determination, referring to the degree to which individuals believe that their vaccination decision is made in autonomy. In the development of the scale, we nevertheless employed other sources as well as qualitative data that we personally collected. The next paragraph will describe all the steps we took to generate and validate a Vaccination Psychological Empowerment Scale (VPES).

## 5.2 Methods

### 5.2.1 *Item generation, content validation and item reduction*

#### 5.2.1.1 *Item generation*

Two researchers (MF and EG) independently generated items based on previous qualitative data collected on parental perceptions of empowerment in the MMR (measles, mumps, and rubella) vaccination decision (Fadda et al., 2016), the conceptualization of psychological empowerment proposed by Spreitzer (Spreitzer, 1995, 1996) and other validated empowerment scales in the context of health (Akey et al., 2000). We employed qualitative data because they can be a valid and enriching tool to inform the design of a survey (Hogan, Greenfield, & Schmidt, 2001; Rowan & Wulff, 2007).

The items were later compared and agreement was reached between the two researchers through extensive discussion and by referring to the sources employed. During this phase, the number of items was reduced, and the items retained were changed and often relocated into a different component. Feedback was also provided on the initial item pool by a team of psychologists from the University of Erfurt, Germany, which allowed for more refinements. A 5-point scale measuring frequency and anchoring at “Never” and “Always” was chosen. The initial item pool consisted of 62 items, generated across six

components: (a) self-determination (21 items), (b) perceived competence (11 items), (c) perceived impact (8 items), (d) perceived meaning (9 items), (e) information orientation (12 items), and (f) gender role preference (1 item). The initial set of items was later submitted for revision to a panel of content and face validity judges.

#### *5.2.1.2 Content and face validation of the scale*

A panel of content experts was asked to review the potential scale items and validate that they are appropriate indicators of the empowerment construct. We contacted 9 individuals based in Italy with expertise in the field of health or psychology and previous experience with survey design, and asked them to participate in this study as content validity judges. All the contacted professionals agreed to participate: four specialists in hygiene and public health, two nurses, one pediatrician, one psychiatrist, and one professor of pedagogy. We created an online survey containing the 62-item pool and sent it to them via e-mail. The survey included the division of items into components, instructions about the revision, an introduction that described the purpose of the study, and a request to provide feedback both on each single item according to clarity and appropriateness, and on the questionnaire as a whole according to completeness and accuracy. Answers were collected between August 1st and September 30th, 2015.

Ninety recommendations were provided for 47 items out of the initial 62. Recommendations involved the rewording of items to reduce ambiguity of meaning (n=54) or their deletion (n=36). The recommendations for item revision were addressed only when they were suggested by at least three jury members. Changes resulted in the rewording of 17 items and the deletion of 5. The 5 deleted items came from 5 different components, and did not eliminate the measurement of any of the scale's components. The final scale resulted in 57 items. Following the panel's suggestion, response options were changed into a 6-point Likert scale measuring agreement and anchoring at "Absolutely disagree" and "Absolutely agree".

### *5.2.1.3 Descriptive assessment and item reduction*

We conducted a pretest with 113 participants to allow for item reduction. A convenience and snowball sampling was used, employing multiple social media platforms. To be eligible, parents had to have at least one child aged up to 10 years old. We sent a link to an online questionnaire to the participants including the content validated 57-item pool and socio-demographic questions such as gender, age, education, origin, number of children and age of the youngest child. Eligibility was assessed through a screening question at the beginning of the survey.

As primary criterion for retaining items, we explored the items' frequency of endorsement and we selected the items showing an endorsement frequency between 0.20 and 0.80. Basing on this criterion, a score from 1 to 5 was attributed to each item. Items were ordered according to their score, and those items scoring 1 or 2 were deleted ( $n = 30$ ). As a secondary criterion to include an item, we used the discrimination index, particularly the Corrected Item-total correlation index. Items with an item-total values higher than 0.3 were selected. Using these criteria, 9 items were retained for the PCA, 3 assessing self-determination, 2 assessing competence, 1 assessing impact, 1 assessing meaning, and 2 assessing information orientation (see Appendix 6).

## *5.2.2 Construct validation*

### *5.2.2.1 Participants*

To assess the convergent and discriminant validity of the scale, participants were recruited through three Vaccination Centers (VCs) in Milan. The diversity of the recruitment locations allowed for different social and cultural backgrounds to be represented in the sample. A consent form was signed by each participant prior to the administration of the questionnaire.

To ensure both pro- and anti-vaccination parents could be represented in our sample, we adopted two recruitment strategies. Parents taking their child for the vaccination were invited to fill out a pen-and-pencil questionnaire in the VCs' waiting

room either before or after their child's vaccination. Inclusion criteria (being a mother/father and having a child younger than 6 years) were checked by the researchers.

To recruit vaccination-adverse parents, the three VCs provided an anonymous list of 72 parents refusing part or all of their child's vaccinations and their telephone numbers. These parents were contacted by phone by the main researchers and asked to fill out online the same survey administered to the pro-vaccination parents. Of the 72 parents contacted, 27 never answered the phone, 15 refused to participate for either lack of time or interest in the study, and 30 accepted to fill out the survey. Of the 30 who accepted, 15 eventually filled out the survey (response rate 33%).

#### 5.2.2.2 *Materials*

Participants received a demographics form, and the revised 9-item Vaccination Psychological Empowerment Scale. The scale was scored on a six-point Likert scale, with higher scores indicating higher empowerment. The scale anchors ranged from "Absolutely disagree" to "Absolutely agree". In addition, measures of convergent and discriminant validity constructs were administered, as well as vaccination-related outcome measures.

#### 5.2.2.3 *Measures of convergent and discriminant validity constructs*

Three instruments originally designed to measure specific components of psychological empowerment and unrelated constructs were used: (1) the General Self-Efficacy Scale (Sibilia, Schwarzer, & Jerusalem, 1995); (2) Spreitzer's Psychological Empowerment Scale adapted to the context of the vaccination decision and used in previous studies (Diviani et al., 2012; Spreitzer, 1995, 1996); (3) the Control Preference Scale adapted to the context of the vaccination decision (Degner, Sloan, & Venkatesh, 1997).

*The General Self-Efficacy Scale (GSES).* The GSES consists of 10 items scored on a 4-point scale anchoring at "Not at all true" and "Exactly true" (Sibilia et al., 1995). The scale is one-dimensional and was created to assess a general sense of perceived self-efficacy in order to predict coping with daily worries as well as adaptation after stressful life events (Schwarzer & Jerusalem, 1995). The final score, ranging between 10 and 40, results from the sum of all answers' scores.

*The Psychological Empowerment Scale (PES).* The original version of the four-dimensional empowerment scale in the work context developed by Spreitzer (Spreitzer, 1995, 1996) consists of 12 items scored on a 7-point Likert scale, although the version used in the current study was adapted to the context of the vaccination decision and scored on a 6-point Likert scale (Diviani et al., 2012). Spreitzer's multidimensional empowerment scale was designed to measure psychological empowerment as a motivational construct manifested in four cognitions (meaning, competence, self-determination, and impact) reflecting an active, rather than a passive, orientation to a work role (Spreitzer, 1995, 1996) and, thus, to an active decision-making process.

*The Control Preference Scale (CPS).* The CPS consists of five cards that portray a different role in treatment decision-making using a statement and a cartoon (Degner et al., 1997). The CPS was developed to assess the role that patients want to play in treatment decision-making (Degner et al., 1997), ranging from the individual making the treatment decisions alone, through the individual making the decisions jointly with the physician, to the physician making the decisions alone. While the original CPS asked subjects to provide their total preference order over the five cards, the scale used in the current study was adapted to the vaccination context by replacing “doctor” with “pediatrician” and asking subjects to indicate their preferred role in their decision-making about their child's vaccination. No cartoon was provided.

#### 5.2.2.4 Vaccination-related outcome measures

In addition to the construct validation measures listed above, we included a number of vaccination-related outcome measures to explore their association with psychological empowerment, since previous studies speculated that higher level of empowerment can lead to vaccine hesitancy (Diviani et al., 2012; Fadda et al., 2016; Schulz & Nakamoto, 2013). These include general knowledge about vaccination using the Vaccination Knowledge scale developed by Zingg and Siegrist (Zingg & Siegrist, 2012), parents' attitude towards vaccination, their confidence in their vaccination decision, the probability they would recommend the vaccination to other parents, their intention to have their child

vaccinated at the next due date, and whether the participants perceived the risks of the vaccination higher than the risks associated with it (Benthin, Slovic, & Severson, 1993).

Moreover, we provided a list and asked participants whom they had talked to about vaccinations in the previous six months. The list included the following options: pediatrician, other medical professionals, homeopath, other complementary and alternative medicine (CAM) professionals, family, friends, and others.

Finally, we asked participants whether they had the same opinion for all vaccinations or whether they would discriminate among them. A blank space allowed the participants to explain for which vaccination they had a different opinion.

#### *5.2.2.5 Socio-demographic variables*

In terms of socio-demographic variables, we asked participants about their gender, ZIP code, number of children, month and year of birth of the youngest child, and both parents' year of birth, level of education and origin (Italy, EU, non-EU).

### **5.3 Results**

#### *5.3.1 Characteristics of the sample*

The final sample included 231 pro- and 14 anti-vaccination parents (see Table 3). Mothers' mean age was 36.9 years ( $SD = 5.25$ ; range = 24-49) while fathers' mean age was 39.6 years ( $SD = 5.8$ ; range = 25-56). Most participants were mothers (74%) and were Italian nationals (85%). More than half of the participants owned an academic degree (66%), resulting in a highly educated sample compared to the statistics for the Lombardy region (Italian National Institute of Statistics, 2017). In line with the statistics for the Province of Milan, about half of the participants (55%) had only one child while the other half (42%) had two or more children (Provincial Statistical Yearbook, 2017). Mean vaccination knowledge was found to be 5.5 ( $SD = 2.4$ ; range = 0-9). Most participants (66%) reported not to discriminate among vaccinations. Those who reported to have a different opinion for measles or MMR ( $n = 21$ ), all non-compulsory vaccinations ( $n = 8$ ), chickenpox ( $n = 7$ ), meningitis ( $n = 6$ ), influenza ( $n = 5$ ), tetanus ( $n = 4$ ), hepatitis B ( $n = 4$ ), pneumococcal

(n = 3), HPV (n = 2), pertussis (n = 2), polio (n = 2), diphtheria (n = 1) and yellow fever (n = 1).

**Table 3.**  
*Characteristics of the participants*

	N = 246 (100%)
Sex	
Mothers	n = 182 (74%)
Fathers	n = 55 (22%)
Both parents	n = 3 (1%)
Age	
Mothers	M = 36.9; SD = 5.25; range = 24-49
Fathers	M = 39.6; SD = 5.8; range = 25-56
Origin	
Italy	n = 209 (85%)
Other EU country	n = 11 (4.5%)
Other non EU country	n = 21 (8.5%)
Education	
University	n = 162 (66%)
High school	n = 55 (22%)
Professional school	n = 12 (5%)
Elementary school	n = 8 (3%)
No education	n = 2 (1%)
Number of children	
1	n = 134 (55%)
2	n = 82 (33%)
3+	n = 21 (9%)
Vaccination behavior	
Vaccination acceptance	n = 231 (94%)
Vaccination refusal	n = 14 (6%)
Vaccination knowledge	M = 5.5; SD = 2.4; range = 0-9
Discrimination among vaccinations	
Discriminates	n = 74 (30%)
Does not discriminate	n = 163 (66%)

### 5.3.2 Factor analytic and rational item selection

We applied principal component analysis (PCA) to analyze the latent structure of the 9-item VPES. The analysis was conducted on the 9 items with orthogonal rotation (Varimax with Kaiser Normalization; Kaiser, 1958). The initial solution explained 55% of the variance with a 3-factor structure. The results showed that the items 1, 6, and 8 loaded on all of the three factors. For this reason, we excluded them from the analysis and the PCA was then conducted on the remaining 6 items. The new solution explained 55.5% of the variance with a 2-factor structure. The results showed that the items number 4 and 5 loaded on both factors, therefore they were excluded and the PCA was conducted again on the remaining 4 items. The new solution explained 77.9% of the variance with a 2-factor structure. The two factors had Eigenvalues over the Kaiser's criterion of 1. Results showed that the Keiser-Meyer-Olkin measure used to verify the sampling adequacy for the analysis ( $KMO = 0.554$ ) could be considered good (Field, n.d.; Hutcheson & Sofroniou, 1999). Bartlett's Test of Sphericity was statistically significant ( $\chi^2=(6)209.037$ ;  $p<.0001$ ), indicating that correlation between the items is strong enough for PCA. Table 4 shows the factor loading after rotation. The items that cluster on the same components suggest that component 1 represents parents' perceived influence of their personal and family experience with vaccination and that component 2 represents parents' desire to ask other parents for their experience with vaccination and their interest in other parents' immunization opinion.



**Table 4.**  
*VPES' factor loading after rotation*

VPES	Component	
	1	2
1. I am interested in what other parents think about childhood vaccinations	<b>.917</b>	.036
2. I like to ask other parents about their experience with their children's vaccinations	<b>.891</b>	.180
3. My decision about my child's vaccinations is especially driven by my personal experiences with vaccinations and diseases	.055	<b>.856</b>
4. My family's experience with childhood vaccinations has an influence on my decision about my child's vaccinations	.142	<b>.833</b>
Eigenvalues	1.93	1.19
% Variance explained	48.29	29.65

The psychometric characteristics of the VPES were investigated for each component. In terms of reliability, the VPES and its components were evaluated for internal consistency as estimated by coefficient alpha. The Cronbach's alpha of the VPES was 0.64. The Cronbach's alpha for the 2 subscales were 0.62 (perceived influence of personal and family experience) and 0.79 (desire to know peers' opinion and experience), respectively.

Since the scoring of the VPES was set on a six-point Likert scale, and the anchors adopted for score reporting are one to six, the possible total scale score range is 4-24. The descriptive statistics for the VPES as a whole and for each component are presented in Table 5. The mean interitem correlation was found to be  $r=.305$ .

**Table 5.**

*Descriptive statistics for the VPES as a whole and for each component*

	N	Range	Minimum	Maximum	Mean	SD	Variance	Skewness		Kurtosis	
Personal and family experience	243	10	2	12	7.57	2.361	5.576	-.384	.156	.019	.311
Other parents' experience and opinion	245	10	2	12	7.26	2.547	6.487	-.256	.156	-.362	.310
VPES	243	20	4	24	14.82	3.859	14.893	-.215	.156	.475	.311

### 5.3.3 Convergent and discriminant validity

The convergent and discriminant validity of the VPES was evaluated by investigating correlations with measures of related and unrelated constructs. The VPES did not correlate with the General Self-Efficacy Scale ( $r=.045, p=.485$ ) or with the Control Preference Scale either ( $\tau b=-.012, p=.825$ ).

In order to compare the VPES with a traditional definition and measurement of psychological empowerment, we computed correlations between the four components of the PES and the two factors of the VPES. We hypothesized that high scores on the first factor (component 1) would indicate lower empowerment, while high scores on the second factor (component 2) would indicate higher empowerment. Results confirmed our hypothesis, showing that the perceived influence of one's personal and family experience had a positive, significant correlation with self-determination ( $r=.152, p=.019$ ) and competence ( $r=.158, p=.015$ ). The two dimensions of competence and self-determination showed to be highly close concepts, correlating strongly and significantly ( $r=.705, p<.000$ ). Correlations with meaning and impact were weak and almost reached statistical significance ( $r=.127, p=.05$  and  $r=.122, p=.061$ , respectively).

As we hypothesized, the empowerment component related to the desire to ask for other parents' experience and know their opinion was negatively correlated with self-determination and the relationship almost reached statistical significance ( $r=-.124, p=.055$ ). A negative, non-significant and weak correlation was also found with competence ( $r=-.052, p=.424$ ). Correlations with meaning and impact were weak and non-significant ( $r=.115, p=.075$  and  $r=.033, p=.617$ , respectively). Following these results, we decided to reverse code the empowerment component related to other parents' experience and opinion in order to compute the final score of the VPES. Thus, the following analyses were conducted using the reverse version of this component.

### 5.3.4 Associations between the VPES and vaccination-related outcome measures

We performed non-parametric analyses since our data did not meet the assumptions of the parametric test. The VPES was found to correlate significantly and positively with parents' vaccination opinion ( $r=.323, p<.000$ ), confidence in the decision ( $r=.266, p<.000$ ),

intention to recommend vaccinations to other parents ( $r=.152$ ,  $p=.02$ ), intention to vaccinate ( $r=.116$ ,  $p=.001$ ), and knowledge ( $r=.315$ ,  $p<.000$ ).

We computed an index to represent the number of people each participant had spoken to about vaccinations (pediatrician, CAM professionals, etc.). The VPES was significantly and negatively correlated with the number of people the participant had referred to ( $r=-.176$ ,  $p=.007$ ). We also explored whether there was a significant difference in the VPES score between participants who had spoken about the vaccination with the pediatrician in the past 6 months and those who did not. We computed an independent sample Mann Whitney U test and found that there was a significant difference ( $U=2945$ ;  $p=.005$ ). Those who had not spoken to the pediatrician had a higher score on the VPES. There was a significant difference also between those who discriminate across vaccinations and those who do not as computed through the Mann Whitney U Test ( $U=7244$ ,  $p=.002$ ). Those who have the same opinion for all vaccinations ( $M=14.69$ ,  $SD=2.74$ ) have a higher VPES compared to those who discriminate among vaccinations ( $M=13.42$ ,  $SD=3.02$ ).

#### *5.3.5 Association between the VPES and socio-demographic variables*

We did not find significant difference in the VPES score according to gender, origin and number of children. The same applies to age and level of education.

### **5.4 Discussion**

The purpose of the current study was to develop a valid and reliable measure of psychological empowerment to be used in the context of parents' vaccination decision, as well as to propose a context-specific definition of this construct. Contrary to the traditional conceptualization of psychological empowerment proposed by Spreitzer as a set of four sub-dimensions (perceived competence, self-determination, impact and meaning; Spreitzer, 1995, 1996), our findings indicate that empowerment in the vaccination decision is a construct composed by two sub-dimensions, one indicating parents' perceived influence of their own and family experience, and one indicating their desire to know other parents' vaccination experience and opinion. The latter dimension was reverse coded,

indicating higher empowerment among those parents who do not wish to know their peer's experience with vaccination and who are not interested in their immunization opinion. The first dimension, whose items were originally designed to measure the sub-dimension of self-determination, stresses the perceived influence of parents' personal and family experience with vaccinations when it comes to make an immunization decision. In Empowerment Theory, the ability to identify the factors that influence one's decision-making is crucial to reach critical awareness, or the understanding of one's social situation (Zimmerman, 2000). The second dimension's items were originally designed to measure the sub-dimension of information orientation. Traditionally, empowerment refers to an active role orientation, the understanding of one's environment, and the strive to obtain needed resources (Spreitzer, 1995, 1996; Zimmerman, 2000). In this case, this is translated into the desire to actively ask for their peers' opinion and their interest for their peers' experience. The two dimensions move in opposite directions.

Concerning the first dimension, the role of one's previous experience with diseases and vaccinations on the immunization decision has been studied extensively. Freeman & Freed (1999) found that parents who vaccinated or intended to vaccinate reported past experience with a disease among family members or friends more frequently compared to non-vaccinators (Freeman & Freed, 1999). Furthermore, studies found that parents who had previously vaccinated their children had higher intentions to vaccinate (Brown et al., 2011; Le Menach et al., 2014). As for the second dimension, which stresses the importance of peers in the vaccination decision, the importance of vaccinating as a social norm has also received significant attention. Family member's belief that the child should be vaccinated predicted vaccination status (Lin et al., 2006), while the belief that immunization is a social norm has been found to predict both intention (Harmsen et al., 2012) and receipt (Allison et al., 2010).

We did not find an association between the VPES and the General Self-Efficacy Scale. Our data seem to suggest that, in the context of the vaccination decision, the dimension of perceived competence does not play an important role. The final VPES measures parents' perceived importance of their own and family experience with vaccination and their desire to know and ask for their peers' experience and opinion on

immunization, while Bandura's original concept of self-efficacy indicates people's beliefs about their ability to perform a given behavior (Bandura, 1994). Furthermore, the General Self-Efficacy Scale is not context-specific. This can explain the lack of correlation with the VPES, stressing the need to adapt scales to their specific context of application. The VPES did not correlate with the Control Preference Scale either. This is because the CPS aims to assess the role that parents want to play in the vaccination decision-making against that of the pediatrician (Degner et al., 1997). The VPES does not consider the role of the pediatrician, but rather that of one's family or other parents.

We found that the personal and family experience component of the VPES had a positive correlation with two empowerment's sub-dimensions, i.e. self-determination and competence. This indicates that the more parents rely on their personal and family's experience, the more they feel able to make a sound vaccination decision and the more they feel autonomous in their decision-making. This is in line with self-determination theory (SDT), according to which perceived autonomy and competence are two strictly related concepts that contribute to fostering motivation and engagement (Deci & Ryan, 2000; Ryan, 2012). On the other hand, our results indicate that the desire to know peers' opinion and experience was negatively correlated with self-determination, meaning that those who tend to look for external reassurance and confirmation among their peers will perceive themselves as less autonomous in the vaccination decision. This finding is confirmed by previous studies grounded in the SDT that found that self-determined behaviors are those that spring from the self, in opposition to those that are pressured by others (Patrick & Williams, 2012).

Another finding is that parents consulting multiple categories of people as well as those avoiding any talk about vaccination with the pediatrician scored higher on their empowerment. In practice, this can be explained because, according to the Italian vaccination system, parents do not necessarily have to consult a pediatrician or other medical professionals before taking their child for the vaccination, since they receive all medical forms and information leaflets at home from the local vaccination center before the appointment. From a more theoretical point of view, this confirms once again the idea

that empowered decisions originate from oneself rather than following consultation with others (Deci & Ryan, 2000; Ryan, 2012).

Regarding the relationship between empowerment and vaccination-related outcome, it appears that highly empowered parents, that is parents who base their immunization decision more on their personal experience rather than on their peers' opinion and experience, are objectively more knowledgeable about vaccinations, more likely to vaccinate and to recommend the vaccination to other parents, more confident with their vaccination decision, and more in favor of vaccinations. The interpretation of this finding is twofold. On the one hand, this reiterates the importance of parents' personal experience with vaccination and disease on different vaccination outcomes. As indicated above, other studies found that previous experience is a predictor of vaccination intention or behavior (Freeman & Freed, 1999). On the other hand, these results shed more light on the potential perils of asking peers for their vaccination opinion and experience. Considering that previous studies found that parents are more likely to trust other parents when it comes to receive vaccination-related information (Haase & Betsch, 2012) and that the Web is rich in anti-vaccination narratives proposed by anti-vaccination advocates (Fadda, Allam, & Schulz, 2015; Haase & Betsch, 2012; Kata, 2012), it does not surprise that lower empowerment scores are associated with negative vaccination-related outcomes.

A last finding is that having the same opinion for all vaccinations is also associated with higher empowerment. This can be explained by previous findings that self-determination predicts satisfaction with one's behavior and decisions (Martin & Paul Hill, 2012; Taylor, Ntoumanis, & Standage, 2008; Zuckerman, Porac, Lathin, & Deci, 1978). Thus, having a high empowerment leads to a more stable opinion about immunization, with a resulting spillover effect that invests all vaccinations.

From a theoretical point of view, our results show that decisional empowerment is different from behavioral when applied in the vaccination decision context (in our case, where parents chose for their children rather than for themselves). In this study, psychological empowerment has lost most of its traditional references to competence, impact and meaning (Spreitzer, 1996; Zimmerman, 1995), narrowing down to a mere

matter of basing the decision on one's personal and family experience vs. the desire to know and actively ask for other parents' opinion and experience.

### **5.5 Limitations and conclusions**

Our study showed that the VPES is a valid and reliable instrument to measure psychological empowerment among parents who are making a vaccination decision for their children. Furthermore, the low number of items and the high explanatory power of the instrument make it a parsimonious, effective and easy administration tool.

Our results allowed for a new, context-specific conceptualization of psychological empowerment as a two-dimensional construct. Empowerment seems to be constituted by a combination of two dimensions: the tendency to base one's decision on one's own and family experience, on the one hand, and the desire to know and ask for other parents' opinion and experience, on the other. Moreover, the two dimensions appeared to be working in opposite directions.

This study is not without limitations. First of all, our recruitment system might have led to self-selection biases in the sample, which resulted in a low number of anti-vaccination parents. Secondly, validating a scale in a different region or country might have led to different results and, thus, to a different conceptualization of the empowerment construct.

While the literature on the predictors of the vaccination decision abounds (Favin et al., 2012), parents' empowerment in the vaccination decision as a possible driver of their immunization behavior has not catalyzed sufficient attention. Our results confirm the importance of recognizing, promoting and maintaining empowerment in the vaccination decision. In practical terms, institutions in charge of carrying out vaccination promotion activities and vaccine administration should work along two parallel lines. On the one hand, they should make sure parents always take home a positive experience with their children's vaccination, from the moment they are contacted for their first appointment (perhaps, from the moment they make the first encounter with the service during pregnancy), until when they are discarded from the vaccination center and return home. This could be done by offering continuous support, providing tailored



information, and asking parents' for feedback about their children's immunization outcome. On the other hand, institutions should pay attention to parents' social networks, by monitoring them, presenting accurate information whenever they are needed and promoting safe information exchanges.

Finally, future research should employ the VPES with a larger, more representative sample, in order to understand whether the scale is able to discriminate significantly between parents who accepted, rejected or delayed their children's immunization

## Chapter VI

Effectiveness of a smartphone app to increase parents' knowledge and empowerment in the MMR vaccination decision: A randomized controlled trial

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*Abstract*

Researchers are trying to build evidence for mhealth effectiveness in various fields. However, no evidence yet is showing the effectiveness of mhealth on parents' attitudes and behavior with regard to recommended vaccination of their children. The aim of this study was to look into the effects of two smartphone-based interventions targeting MMR vaccination knowledge and psychological empowerment respectively. The interventions used gamification features and videos in combination with text messages. We conducted a 2x2 between-subject factorial randomized controlled trial (absence/presence of knowledge intervention X absence/presence of empowerment intervention) with parents of young children in Italy. We randomly allocated 201 eligible participants to one of the four conditions. Data were collected by questionnaires at baseline and posttest. Primary outcomes were MMR vaccination knowledge, psychological empowerment, risk perception, and preferred decisional role; secondary outcomes included MMR vaccination intention, attitude, confidence, and recommendation intention. A significant gain in vaccination knowledge was reported by all experimental groups compared to the control ( $F(3,179) = 48.58, p < .000$ ), while only those receiving both interventions reported a significant increase in their psychological empowerment ( $t(179) = -2.79, p = .006$ ). Participants receiving the intervention targeting knowledge reported significantly higher intention to vaccinate ( $t(179) = 2.111; p = .03$ ) and higher confidence in the decision ( $t(179) = 2.76; p = .006$ ) compared to the control group. Parent-centered, gamified mobile interventions aimed at providing parents with vaccination-related information can be used to increase their knowledge, their intention to vaccinate as well as their confidence in the vaccination decision.

*Keywords*

MMR vaccination, smartphone app, mHealth, empowerment, knowledge, intervention.

## **6.1 Introduction**

The number of smartphone applications designed for health purposes has grown exponentially in the past fifteen years and is still rapidly rising (Fiordelli, Diviani, & Schulz, 2013). Mobile apps have provided tremendous opportunities to influence people's health behavior thanks to a combination of unique characteristics (Sherry & Ratzan, 2012; Zhao, Freeman, & Li, 2016). They are at the same time personal, connected, easy to use, customizable, empowering, increasingly technological and always at hand (Fiordelli et al., 2013; Klasnja & Pratt, 2012; Wilson et al., 2014). Their range of application is extremely wide and, more recently, they have made an appearance for vaccination-related purposes as well. Immunization apps include features such as: provide information on different vaccinations and on disease activity in a given area (Atkinson et al., 2015; Bednarczyk, Frew, Salmon, Whitney, & Omer, 2017; Wilson, Atkinson, & Penney, 2015), calculate one's risk of catching a disease (Panatto et al., 2016), offer a reminder about vaccines (Peck, Stanton, & Reynolds, 2014; Uddin et al., 2016; World Health Organization, 2014; Wilson, Atkinson, & Penney 2015; Wilson, Atkinson, & Westeinde, 2015), and track, record and update immunization information (Katib, Rao, Rao, Williams, & Grant, 2015). The Immunization Action Coalition (IAC) lists 19 free immunization apps directed either to healthcare/immunization providers or to patients/parents and offered by recognized institutions (Immunization Action Coalition, 2017), but a search with the keyword "vaccin\*" on Google Play generates as many as 249 results (Google Play, 2017).

Despite coming from reliable and certified organizations, a major limitation of almost all immunization apps is the lack of evidence of their effectiveness, as a recent review also concluded (Odone et al., 2014). As a matter of fact, only one immunization app directed at parents has been tested empirically (Atkinson et al., 2016). This is the first study aiming at testing in a randomized controlled trial two versions of a smartphone-based application, one to increase parents' knowledge about the MMR vaccination and the other to augment empowerment in the MMR vaccination decision. The theoretical background is provided by the Health Empowerment Model. In this model, Schulz and Nakamoto (Schulz & Nakamoto, 2013) suggested that acceptance or

refusal to vaccinate one's child might arise from several factors including beliefs based on completely or partly incorrect information (knowledge), in addition to a more or less strong sense of autonomy (empowerment).

The intervention targeting knowledge employed the device of gamification. Gamification is defined as “the use of game design elements in non-game contexts” (Deterding, Björk, Nacke, Dixon, & Lawley, 2013; Deterding, Khaled, Nacke, & Dixon, 2011). It represents an increasingly popular field of research and application due to its potential to increase users' engagement (Allam, Kostova, Nakamoto, & Schulz, 2015; Denny & Paul, 2013; Eickhoff, Harris, De Vries, & Srinivasan, 2012; Love et al., 2016), satisfaction (Downes-Le Guin, Baker, Mechling, & Ruylea, 2012; Eickhoff et al., 2012; El Tantawi, Sadaf, & AlHumaid, 2016), enjoyment of activities (Drace, 2013; Flatla, Gutwin, Nacke, Bateman, & Mandryk, 2011; Li, Grssoman, & Fitzmaurice, 2012), task performance (Li, Grssoman, & Fitzmaurice, 2012; Hamari, 2013; Jung, Schneider, & Valacich, 2010), participation (Denny & Paul, 2013; Halan, Rossen, Cendan, & Lok, 2010), empowerment (Allam et al., 2015), learning (Domínguez et al., 2013; El Tantawi et al., 2016; Hakulinen, Auvinen, & Korhonen, 2013; Knight et al., 2010; Mokadam et al., 2015; Smith & Baker, 2011; Theng, Lee, Patinadan, & Foo, 2015), attitude (Denny & Paul, 2013; Domínguez et al., 2013; Hamari & Koivisto, 2013), and in reinforcing a behavior (Theng et al., 2015).

The intervention targeting empowerment employed a narrative presented by a video format and interpersonal communication elements through text messages (Cugelman, Thelwall, & Dawes, 2011). Recent studies found that web-based interventions to increase patient empowerment had positive effects (Camerini & Schulz, 2012; Kuijpers, Groen, Aaronson, & van Harten, 2013; Samoocha et al., 2010; Shearer, Fleury, Ward, & O'Brien, 2012) and that the use of both narratives and interpersonal communication may influence health outcomes and one's vaccination decision, as well as facilitate decision-making (Betsch et al., 2011, 2013; Brown & Sevdalis, 2011; Bylund & Duck, 2004; Haase & Betsch, 2012; Heiss, Carmack, & Chadwick, 2015; Willis et al., 2013).

Grounded in the theoretical model, the goal of this study is to target the two constructs of knowledge and empowerment through a smartphone app and enhance their effects on MMR vaccination future behavior, attitude and recommendation, while testing, in a similar approach, the use of interpersonal communication and gamification as boosters. This is the first RCT that includes gamification, visual narrative, and interpersonal communication features as part of an experimental manipulation and studies the effect of a smartphone app targeting vaccination knowledge, respectively literacy, and empowerment on vaccination-related decisional and behavioral outcomes of parents of young children.

## **6.2 Results and discussion**

### *6.2.1 Participants' characteristics*

Initially, 255 participants agreed to participate to the study and 233 accessed the baseline questionnaire. Of these, 26 did not meet the inclusion criteria and 5 did not complete the baseline questionnaire. We randomly allocated the resulting 202 subjects to one of the three experimental groups or the control group. After the post-test survey was closed, 5 subjects were removed from the control group as they reported having known the app. We further removed 13 subjects who did not access the app or did not complete the post-test survey. The final sample (N=184) was mainly composed by mothers (94.6%), highly educated parents (60.4%) and Italian nationals (98.4%). The average age was 34.2 years ( $SD = 4.66$ ;  $range = 21-47$ ) and most participants had only one child (77%). Participants' characteristics can be found in Table 6.

**Table 6.**  
*Participants' characteristics*

	Experimental group				Tot.
	1	2	3	4	
	n=48 (26%)	n=45 (24%)	n=47 (26%)	n=44 (24%)	N=184 (100%)
Age	M=33.44, SD=4.27	M=34.49; SD=4.46	M=33.98, SD=4.86	M=35 SD=5.06	
Gender					
Women	n=43 (25%)	n=43 (25%)	n=46 (26%)	n=42 (24%)	174 (95%)
Men	n=5 (50%)	n=2 (20%)	n=1 (10%)	n=2 (20%)	10 (5%)
Nationality					
Italy	n=45 (25%)	n=45 (25%)	n=46 (26%)	n=43 (24%)	179 (97%)
Brazil	-	-	n=1 (100%)	-	1 (1%)
Morocco	n=1 (100%)	-	-	-	1 (1%)
Mexico	n=1 (100%)	-	-	-	1 (1%)
Education					
Middle	n=3 (75%)	-	n=1 (25%)	-	4 (2%)
School					
Professional	n=4 (36%)	n=2 (18%)	n=2 (18%)	n=3 (28%)	11 (6%)
School					
High Sch.	n=17 (30%)	n=13 (23%)	n=13 (23%)	n=14 (24%)	57 (31%)
University	n=23 (21%)	n=30 (27%)	n=31 (28%)	n=26 (24%)	110 (60%)
Number of children					
1	n=40 (27%)	n=35 (25%)	n=35 (25%)	n=33 (23%)	143 (78%)
>1	n=8 (20%)	n=10 (24%)	n=12 (29%)	n=11 (27%)	41 (22%)

### 6.2.2 Randomization Check

We found no significant differences across the four groups in terms of participants' age ( $F(4,179) = 0.94$ ;  $p = .42$ ), gender ( $\chi^2 = 3.47$ ;  $p = .32$ ), educational level ( $F(4,179) = 2.24$ ;  $p = .08$ ), number of children ( $\chi^2 = 6.18$ ;  $p = .72$ ), control preference ( $\chi^2 = 10.90$ ;  $p = .54$ ), nationality ( $\chi^2 = 8.67$ ;  $p = .47$ ), age of youngest child ( $F(4,179) = .634$ ;  $p = .59$ ), empowerment ( $F(4,179) = .431$ ;  $p = .73$ ) and knowledge ( $F(4,179) = .79$ ;  $p = .5$ ).

### 6.2.3 Primary outcomes

The covariate, pre-experiment knowledge, was significantly related to the post-experiment knowledge ( $F(4,179) = 82.07$ ;  $p < .000$ ). There was a significant main effect of the experimental group on the level of post-experiment knowledge after controlling for the effect of pre-experiment knowledge ( $F(3,179) = 48.58$ ;  $p < .000$ ). Planned contrasts revealed that all three experimental groups increased post-experiment knowledge compared to the control group (knowledge intervention only  $t(179) = 9.11$ ;  $p < 0.000$ ; empowerment intervention only  $t(179) = 4.40$ ;  $p < .000$ ; both interventions  $t(179) = 11.00$ ;  $p < .000$ ). Interestingly, all pairwise comparisons between experimental groups also showed significant differences. The group receiving both interventions has the highest knowledge gain, followed by the group receiving the knowledge intervention only, the empowerment intervention only and, finally, the control group with the lowest knowledge level. This indicates that empowering parents will increase their information seeking and favor learning; giving the information also increases their knowledge, but it is only by giving the information and pushing them to search for more information that the highest gain is generated. Further results confirmed between groups differences in terms of online information seeking ( $F(3,180) = 11$ ;  $p = <.000$ ). A t-test revealed that participants receiving both interventions searched information more often compared to those in the knowledge intervention only group ( $t(93) = 2.09$ ;  $p = .04$ ).

The covariate, pre-experiment empowerment, was significantly related to the post-experiment empowerment ( $F(4,179) = 77.750$ ;  $p < .000$ ). There was a significant main effect of the experimental group on the level of post-experiment empowerment after controlling for the effect of pre-experiment empowerment ( $F(3,179) = 2.74$ ;  $p = .04$ ). Planned contrasts revealed that the knowledge intervention only did not increase post-experiment empowerment compared to belonging to the control group ( $t(179) = 1.68$ ;  $p = .09$ ), as well as belonging to the empowerment only group ( $t(179) = 1.03$ ;  $p = .302$ ). However, receiving both interventions increased post-experiment empowerment against the control group ( $t(179) = -2.79$ ;  $p = .006$ ). This suggests that shift in empowerment can take place only when empowering interventions also offer tangible information about the domain where empowerment is advocated.



#### 6.2.4 Secondary outcomes

The ANCOVA that was conducted to determinate any between groups difference in terms of “*post-experiment intention to vaccinate*” showed a significant main effect ( $F(3,179) = 4.287$ ;  $p = .006$ ). Planned contrasts revealed that the group receiving the intervention addressing vaccination knowledge showed a stronger post-experiment intention compared to the control group ( $t(179) = 2.111$ ;  $p = .03$ ). On the other hand, the group receiving the intervention addressing empowerment ( $t(179) = -1.156$ ;  $p = .24$ ) and the group receiving both interventions ( $t(179) = -.737$ ;  $p = .46$ .) showed similar intention to vaccinate compared to the control group. As expected, the pre-experiment intention was significantly related to the post-experiment intention ( $F(4,179) = 71.83$ ;  $p < .000$ ).

Similar results were found analyzing the “*post-intervention confidence in the vaccination decision*”. There was a significant main effect of the experimental conditions on the level of post-experiment confidence after controlling for the effect of pre-experiment confidence ( $F(3,179) = 4.44$ ;  $p = .005$ ). Planned contrasts revealed that belonging to the group receiving the knowledge intervention increased the post-experiment confidence compared to belonging to the control group ( $t(179) = 2.76$ ;  $p = .006$ ). On the other hand, belonging to the group receiving the empowerment intervention ( $t(179) = -0.665$ ;  $p = .5$ ) or to the group receiving both interventions ( $t(179) = .056$ ;  $p = .62$ ) did not have an impact on the post-experiment confidence compared to the control group. The covariate, pre-experiment confidence, was significantly related to the post-experiment confidence ( $F(4,179) = 156.04$ ;  $p < .000$ ).

First of all, these findings suggest that increasing parents’ knowledge about the vaccination by gamification will lead to an increase in their vaccination intention. This is in line with the literature, which found an association between poor objective knowledge of the vaccination and delayed or refused vaccination status (Borràs et al., 2009; Humiston et al., 2005; Miller et al., 1994; Rahman et al., 1995) as well as lower intention to vaccinate as predicted by poor subjective knowledge about the vaccine (Freeman & Freed, 1999).

Second, the empowerment intervention did not have the desired effect on vaccination intention, and neither did the combination of both interventions. The latter

result is unexpected, though there could be possible explanations. First, considering that the empowerment intervention invited participants to search information and make an autonomous and informed decision, it could be that an information overload might have confused them. Secondly, in light of many parents being aware that the vaccinations in question were officially recommended, a call for an autonomous decision might have been understood as a call for a decision against the official recommendation. A third and simpler explanation is that the intervention combining both strategies is excessively complicated as well as cognitively and emotionally demanding. Research has found that combined interventions are not always more efficient than simple interventions employing one strategy (Tanash, Fitzsimons, Coates, & Deaton, 2017).

Another finding is that there was no significant main effect of the experimental group on the level of post-experiment opinion after controlling for the effect of pre-experiment opinion ( $F(3,179) = 1.02; p = .38$ ). As expected, the pre-experiment opinion, was significantly related to the post-experiment opinion ( $F(4,179) = 99.76; p < .000$ ). Similarly, there was no main effect of experimental conditions on the post-experiment recommendation intention ( $F(3,179) = 1.54; p = .24$ ). Also in this case, the pre-experiment recommendation intention was significantly related to the post-experiment recommendation intention ( $F(4,179) = 98.8; p < .000$ ).

The first insignificant findings could be ascribed to the operationalization of opinion in the survey. The response options (“Against” to “In favor”) differed significantly from those proposed for intention, which rather measured probability. The lack of significant results in the second case are to ascribed to the fact that, while intention and opinion are theoretically related, the concept of referral or recommendation might depend from personality factors or from parents’ previous experience with the vaccination staff and facilities (Daneault, Beaudry, & Godin, 2004; Hill & Doddato, 2002).

## **6.3 Materials and methods**

### *6.3.1 Sample*

Recruitment of the participants lasted from April until November 2016. A marketing agency was contacted to send the study invitation to potential participants by email. To be

eligible, participants had to (a) have at least one child born after September 1, 2015<sup>3</sup>, (b) be resident in Lombardy<sup>4</sup>, one of the twenty administrative regions of Italy, and (c) own a smartphone with Internet connection. The final sample was composed by 184 subjects divided into four groups.

### 6.3.2 Experimental Design

A smartphone application was developed in order to deliver two interventions, one targeting MMR vaccination literacy and the other targeting empowerment in the MMR vaccination decision. The study design was a 2x2 between-subject factorial randomized controlled trial. The factors studied were presence or absence of two interventions, resulting in four possible experimental groups. Participants were randomly allocated to one of the 3 experimental groups or to the control condition. The first group received the app containing only the intervention targeting the MMR literacy, the second one received the app containing only the intervention targeting empowerment and the third one received the app containing both the knowledge and empowerment interventions. The control group did not receive the app.

In the first intervention aimed at increasing participants' literacy about the MMR vaccination, users received 35 questions distributed on a time span of 10 days. Once answered, each question unblocked an explanation of the answer through textual content. Each correct answer would earn participants a number of points according to the weight of each question, while no points were given for wrong answers or if no answer was given by midnight of the day (Lewis, Swartz, & Lyons, 2016). To provide a gamified experience, participants could see their score and compare it to that of the other participants through a leaderboard. Furthermore, participants were awarded a shopping voucher the value of which increased with their performance in the quiz (Cameron, Banko, & Pierce, 2001). All questions, answers, and contents were developed following a review of the scientific literature on parents' decision on the MMR vaccination (Brown et al., 2010; Favin et al.,

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<sup>3</sup> Since the first dose of the MMR vaccination is given between 12-15 months we sampled among parents of young children to avoid cognitive dissonance bias (Festinger, 1962).

<sup>4</sup> We decided to recruit our participants in Lombardy because this is the most densely populated region in Italy (Italian National Institute of Statistics, 2017).

2012; Mills et al., 2005; European Centre for Disease Control and Prevention, 2013; Serpell & Green, 2006; Wheelock, Parand, et al., 2014; Yaqub et al., 2014) and of major public health websites (CDC, ECDC, NHS), and later validated by a panel of medical experts based in Italy. We asked the panel members to identify any inaccurate, inappropriate or incomplete information and suggest possible alternatives, as well as decide on each question's weight (from 1 to 5 points) in terms of importance.

In the second intervention, aimed at enhancing psychological empowerment, users received two videos (one on the first day lasting four minutes and one on the last day lasting approximately one minute) and eight messages. We developed the script of messages and the two videos following Spreitzer's conceptualization of empowerment as a set of four sub-dimensions: competence, self-determination, importance and impact. In addition, we included active information orientation as a fifth sub-dimension of empowerment, following our previous qualitative work on parental psychological empowerment in the vaccination decision (Fadda et al., 2016). In the two videos, an actress acting as a mother reports that she became able to make an empowered decision about MMR by collecting reliable information from multiple sources, and by thinking about the importance and the impact of the decision. In the end, she addresses her audience encouraging them to make an informed, empowered decision. The video's viewer was addressed in the second person in order to increase participant's involvement (Franklin, Waller, Pagliari, & Greene, 2006). Text messages were designed to reinforce the messages delivered in the video. We designed the app to send up to three notifications per day as a reminder to complete the quiz, watch the video/s or read the messages.

We developed our application according to Cugelman's gamification tactics (Cugelman, 2013; Cugelman et al., 2011) and to a number of related techniques (see Appendix 7). Since gamification should offer a long-term resource to be considered effective (Cugelman, 2013), without reaching a point of saturation where its appeal decreases, we set the duration of the application's tasks at 10 days.

### 6.3.3 MorbiQuiz sections and features

The smartphone app, called MorbiQuiz, was entirely developed by researchers with expertise in health communication, mHealth and psychology, and it was created with the collaboration of an agency specialized in native app development. The application is in Italian, it runs on the two operating systems iOS and Android, and can be downloaded free of charge on the Italian and Swiss Google Play and App Store.

The app consists of three main screens: a main screen, a lateral menu, and a leaderboard. In the intervention targeting vaccination literacy, the main screen displays the participant's path, dotted by 10 points, each representing a daily quiz (Figure 9).



**Figure 9.** App's main screen

The dot lights up when the quiz is completed and allows participants to visualize the questions answered, the correct answers, the score for each answer, and the textual content associated with the answer (Figure 10).

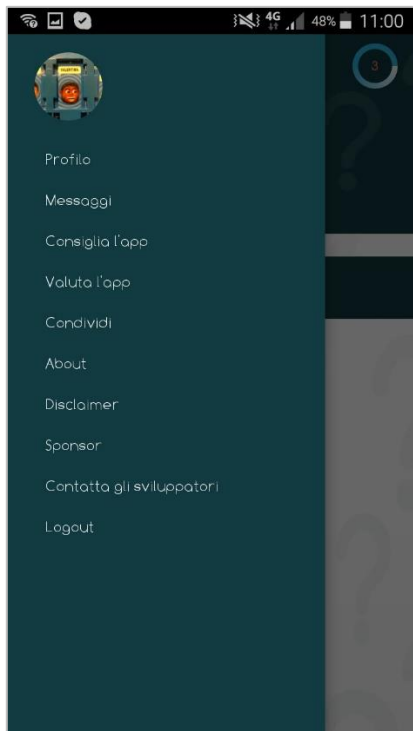


**Figure 10.** App's screen showing the questions answered, the correct answers, the score for each answer, and the textual content associated with the answer

In the second intervention, targeting vaccination empowerment, the participant's path has only two dots, standing for the two videos. The dots light up when a video was watched and, by clicking on it, the participants can see the video again. The main screen of the group receiving both interventions displays a 10-dot path with the two videos integrated in the first and last dots respectively.

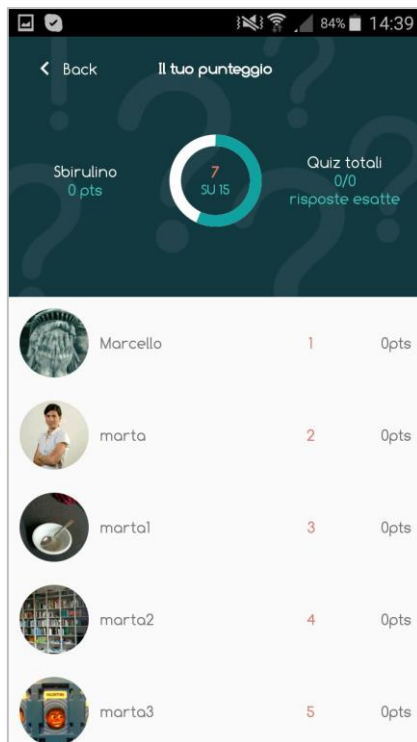
The lateral menu (Figure 11) has the following features: (a) a profile section – where participants can select their gender, nickname and profile picture; (b) a message section, where participants can read all messages received until that point (only available for the two experimental groups receiving them); (c) the option to recommend the app by e-mail; (d) the option to evaluate the app in the official store; (e) the option to share the app (e.g. via WhatsApp or other social media); (f) an “about” section; (g) a disclaimer; (h)

the list of all institutions working on the project; (i) the option to contact the developers; (l) a logout option.



**Figure 11.** App's lateral menu

The leaderboard (Figure 12) displays all participants' nicknames, profile pictures, and respective scores, with the highest scores on top. Finally, the researchers had the access to a dashboard, which allowed to constantly keep track of participants' usage of the app and download usage-related data in real time.



**Figure 12.** App's leaderboard

#### 6.3.4 Procedure

Before starting the experiment, participants received an invitation containing a unique ID number, an online questionnaire (baseline survey), and a consent form. We sent up to two reminders to fill out the survey, which closed on November 20. Once the questionnaire was closed, we randomly allocated all eligible participants to one of the four conditions.

On November 23, we provided participants in the three experimental conditions with further instructions on how to download and access the app through generated accounts with unique username and password. We included information on the (maximum) voucher amount they would receive as a compensation for their participation. We set the amount at 10 euros for the group receiving only the empowerment intervention and the control group, while participants receiving the knowledge intervention or both interventions could obtain up to 50 euros according to their final score (approximately 43



eurocents per point, for a maximum of 117 points). The control group was informed that they would only receive a second questionnaire after two weeks.

Application of the two interventions lasted 10 days and took place simultaneously for all participants between December 1 and December 10, 2016. Once logged in, participants were asked to select their gender, include a public nickname and upload a profile picture. Once the experiment was finished, all participants received a posttest questionnaire aiming to measure the same primary and secondary variables assessed during the baseline survey. The questionnaire was closed on January, 15<sup>th</sup>, 2017.

### *6.3.5 Measures*

The baseline questionnaire and the posttest used the same questions and exact wording for all primary and secondary measures. In the pretest, we also assessed subjective health of the participant and of his/her child as an ice-breaking question, and we added four extra items for those participants who had more than one child to compensate for recall bias (Festinger, 1962). These four items asked about: (a) vaccination status of older children (vaccinated with 1, 2 or no doses), (b) past experience with MMR side effects (on a 5-point scale anchoring at “mild” and “severe”), (c) if participant uses the same or different criteria to make an MMR vaccination decision for the youngest child compared to the older one(s), and (d) to evaluate the MMR vaccination decision for the youngest child compared to the older ones (on a 9-point scale anchoring at “easier” and “more difficult”). The posttest also included questions regarding: (a) information seeking in the past 30 days; (b) any events that had prevented active participation in the experiment (such as child’s or own sickness, travel, lack of Internet or smartphone access for one or more days); (c) any conversation on the MMR vaccination or other vaccinations with other people in the past 30 days (pediatrician or other medical professional, homeopath or other CAM professional, friends or relatives); (d) user’s evaluation of the app. To evaluate the app, we adapted 11 items from the Mobile App Rating Scale (Domnich et al., 2016; Stoyanov et al., 2015).

#### 6.3.5.1 Primary outcomes

Psychological empowerment was measured with 12 items developed by Diviani and colleagues (Diviani et al., 2012). The scale follows Spreitzer's conceptualization of psychological empowerment as a set of four sub-dimensions (Spreitzer, 1995). Response was recorded on a 7 point-scale measuring agreement. The final score is the sum of all answers, with a range from 12 to 84. MMR vaccination knowledge was measured with 15 items. Eight items were adapted from the vaccination knowledge scale (Zingg & Siegrist, 2012) while seven items were created *ad hoc* to cover a number of notions included in the app, such as current vaccination coverage in Italy and typology of vaccination facilities. Response was recorded as either "True", "False" or "I don't know". Correct answers were scored as 1, while other options obtained no score. The final score is the sum of all correct answers, ranging from 0 to 15. Risk perception of the MMR vaccination side effects and of measles was measured with four items, two about severity and two about susceptibility. Furthermore, we asked participants to compare the risks and benefits of the MMR vaccination against those of its target diseases with a single item adapted from a risk perception scale (Benthin et al., 1993).

#### 6.3.5.2 Secondary outcomes

The secondary outcomes were MMR vaccination attitude, intention to vaccinate against MMR, intention to recommend the MMR vaccination to other parents and confidence in the decision. All variables were measured with a single item scale and response was recorded on a 5-point scale. Furthermore, participants' preferred role in the MMR vaccination decision was measured with the Control Preference Scale (CPS), adapted to the vaccination context by replacing "doctor" with "pediatrician" and asking subjects to indicate their preferred role in their child's MMR vaccination decision-making (Degner et al., 1997).

### 6.3.5.3 Control variables

Socio-demographic information included both parents' age, level of education, nationality and ZIP code. In addition, parents indicated the date of birth of their only child or, if they had more than one child, their youngest one.

### 6.3.6 Statistical analysis

Data analysis was performed using the Statistical Package for Social Science (SPSS; Version 21.0). After entering the collected data into the software, missing data and outlier checks were performed, as well as shape of distribution analyses. In order to ensure that results could be ascribed to the experimental conditions rather than to baseline between-group differences, randomization checks were performed using ANOVAs and contingency coefficients. ANCOVAs were performed for each primary and secondary outcome to determine whether there were differences among the experimental conditions in terms of "post-experiment outcome" after controlling for its "pre-experimental" level. Where appropriate, planned contrasts were conducted to analyze significant differences across the experimental conditions.

## 6.4 Limitations

This study is not without limitations. First of all, the self-selected nature of our sample resulted in a low number of parents contrary to or undecided about their child's MMR vaccination. Second, as significant between-group differences were detected for intention and confidence, it might be that insignificant findings are to be ascribed to limitations related to the operationalization and measurement of the other secondary outcomes. Finally, since the study was advertised by academic institutions, it may have mostly attracted the attention of educated parents. Therefore, sampling among less educated participants might generate different findings. Finally, there's the possibility of confounding because the groups receiving the knowledge intervention were potentially offered a higher monetary incentive compared to the empowerment only group.

### **6.5 Implications and conclusions**

Our work suggests that multi-component mHealth interventions aimed at providing parents with vaccination-related information can be effective in boosting their knowledge and increasing their intention to vaccinate (Jackson et al., 2011; Shourie et al., 2013). Furthermore, it seems that offering a gamified learning experience can significantly contribute to a knowledge gain in the context of vaccination. Interventions aimed at increasing parents' empowerment, on the other hand, should cautiously consider a possible information overload as a drawback that can ultimately confuse parents, and also be aware that a call for empowerment might be misread as a call against adhering to official recommendations. Future qualitative research could be relevant to help explain the experimental results, as well as explore parents' experience with the app we developed and their suggestions on possible implementations of this tool. Our study provides further evidence for the suitability of the mHealth context for experimental studies as its versatility allows for different experimental treatments.

## Chapter VII

Evaluation of a smartphone-based intervention to increase parents' knowledge about the MMR vaccination and their psychological empowerment: A mixed method approach

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*Abstract*

The aim of this study is to evaluate two smartphone-based interventions aimed at increasing parents' knowledge of the MMR vaccination (through elements of gamification) and their psychological empowerment (through the use of narratives), respectively. The two interventions were part of a randomized controlled trial. We conducted two studies with the RCT participants: an online survey aimed at assessing their rating of the tool regarding a number of qualities, such as usability and usefulness, and qualitative telephone interviews to explore participants' experiences with the application. The results of the survey showed that participants receiving the knowledge intervention (alone or together with the empowerment one) liked the app significantly better compared to the group that only received the empowerment intervention. Parents receiving the empowerment intervention complained that they did not receive useful information but were only invited to make an informed, autonomous MMR vaccination decision. The results suggest that empowering efforts should always be accompanied by the provision of factual information. Using a narrative format that promotes parents' identification can be an appropriate strategy, but it should be employed together with the presentation of more points of views and notions regarding, for instance, the risks and benefits of the vaccination at the same time.

*Keywords*

Evaluation, MMR, vaccination, smartphone application, knowledge, empowerment.

## **7.1 Introduction**

Childhood vaccination coverage is generally high in most developed countries, but more or less homogeneous groups of unvaccinated individuals indicate that the phenomenon of vaccine hesitancy remains a significant problem (Dubé et al., 2013). To decrease vaccine hesitancy, which includes not only refusing some or all recommended vaccinations but also accepting them with uncertainty, a number of interventions have been proposed employing different designs and based on various frameworks (Dubé et al., 2015). Sadaf and colleagues (2013) summarized such interventions into three groups: (a) passage of state laws (such as school immunization requirements), (b) state- and school-level implementation of laws (procedural complexities of obtaining nonmedical exemptions and school policies for immunization requirements), and (c) parent-centered immunization interventions, generally with information or education purposes (Sadaf, Richards, Glanz, Salmon, & Omer, 2013). Williams (2014) divided the latter type of interventions in different strategies to improve (1) parental attitudes about childhood vaccines, (2) vaccination intent, or (3) vaccination uptake among vaccine-hesitant parents (Williams, 2014). More recently, Willis and colleagues have proposed a classification that includes seven main categories that can be used in communication interventions targeting parents or soon-to-be-parents, communities members and health care providers: inform or educate, remind or recall, teach skills, provide support, facilitate decision-making, enable communication and enhance community ownership (Willis et al., 2013).

However, a recent review concluded that there is mixed evidence on the effectiveness of vaccination-related interventions involving face-to-face communication interventions, health-care provider training, community-based actions, or communication using mass media (Dubé et al., 2015). A major limitation of most interventions is that they lack a rigorous evaluative assessment (Dubé et al., 2015). In fact, over the last two decades, randomized controlled trials have been increasingly considered as the “gold standards” in evidence-based practice, the only proof of the effectiveness of an intervention and, consequently, as the most important instrument in deciding whether to adopt an intervention or not (Johnson & Schoonenboom, 2016). According to their

supporters, RCTs have great ability “to minimize selection and information bias, control confounding, and for ruling out chance” (Johnson & Schoonenboom, 2016). At the same time, however, RCTs might not be enough to achieve results that are useful in practice (Johnson & Schoonenboom, 2016). In particular, many of the most important issues facing RCT participants - their feelings, hopes, and beliefs, for example - cannot be meaningfully reduced to numbers or adequately understood without reference to the immediate context in which they live (Rao & Woolcock, 2004). Consequently, many authors have argued for conducting RCTs that have been supplemented by research components that are either qualitative, or that are themselves a combination of qualitative and quantitative research components (Johnson & Schoonenboom, 2016). This strategy can provide evidence about how the intervention works (or why it did not), for whom, and under what circumstances (Rao & Woolcock, 2004).

Between December 1 and 10, 2016 our research team delivered two immunization interventions through a smartphone application as a randomized controlled trial (Fadda et al., 2017). The application, called MorbiQuiz, is in the Italian language and can be downloaded free of charge in the Italian and Swiss Google Play and App Store. In the first intervention, aimed at increasing participants’ knowledge about the MMR vaccination using gamification, participants received 35 questions distributed on a time span of 10 days (3-4 questions per day). Once answered, each question unblocked an explanation of the answer through textual content. Each correct answer would earn participants a number of points according to the weight of each question, while no points were given for wrong answers or if no answer was given by midnight of the day. To provide a gamified experience, participants could see their score and compare it to that of the other participants through a leaderboard. Furthermore, participants were awarded a shopping voucher, which increased with their performance in the quiz.

In the second intervention, aimed at enhancing psychological empowerment, users received two videos and eight messages. In the two videos, an actress acting as a mother reports that she became able to make an empowered decision about the MMR vaccination by collecting reliable information from multiple sources, and by thinking



about the importance and the impact of the decision. In the end, she addresses her audience encouraging them to make an informed, empowered decision. The video's viewer was addressed in the second person in order to increase participant's involvement. Regarding the messages, they were designed to reinforce the messages delivered in the video. Participants received either the first, the second or both interventions. A control group did not receive any intervention.

The effect of the two interventions (combined and alone) was tested on a number of outcomes such as vaccination knowledge, psychological empowerment, intention to vaccinate, confidence in the vaccination decision, vaccination opinion, intention to recommend the vaccination, and control preference in the vaccination decision-making. All experimental groups reported a significant increase in their vaccination knowledge compared to the control ( $F(3,179) = 48.58, p < .000$ ), while only those participants receiving the two interventions combined reported a significant increase in their psychological empowerment ( $t(179) = -2.79, p = .006$ ). Only those participants receiving the knowledge intervention had a significantly higher intention to vaccinate ( $t(179) = 2.111; p = .03$ ) and more confidence in the decision ( $t(179) = 2.76; p = .006$ ) compared to the control group.

Since the experiment was only partially successful, we decided to assess the perceptions of the participants on a number of characteristics of the app and explore their experience with this tool.

### *7.1.1 Aims of the study*

The effectiveness of the majority of vaccination interventions using new media, such as immunization apps, is simply evaluated looking at statistics regarding their download and usage (Alqahtani et al., 2016; Bednarczyk et al., 2017; Peck, Stanton, & Reynolds, 2014). These evaluative methods, however, provide no insights into participants' perceptions regarding, for instance, the usability of the target tool. Furthermore, evaluations might be useful not only to collect participants' perceptions but also to assess quantitative findings related to the intervention efficacy or explain why certain features did not have a significant effect on a given outcome.

The broader scope of this study is to evaluate two interventions administered through an application for smartphone (Fadda et al., 2017). The two interventions aimed at increasing parents' knowledge of the MMR vaccination and their psychological empowerment, respectively, and were part of a randomized controlled trial conducted in December 2016. Our two main research questions are:

- (1) How did participants perceive the app's usability and usefulness?*
- (2) What was their experience with the tool and its functionalities?*

In order to answer these questions we conducted two studies with the RCT participants and employed a mixed-method approach. Study 1 describes an online survey aimed at quantifying participants' rating of the tool regarding different qualities, including usability and usefulness, while Study 2 takes the shape of a qualitative exploration of participants' experiences with the application and of their feelings related to its use. The results of these studies will be interpreted in light of the quantitative results of the RCT, and practical implications for the design of future smartphone-based immunization interventions will be discussed.

## 7.2 Study 1

### 7.2.1 Methods

Study 1 takes the shape of an online survey, which was included within the posttest questionnaire we sent via e-mail or WhatsApp to the participants immediately after the end of the experiment. To be included in Study 1, participants had to have at least one child younger than 15 months, to be a resident in the Lombardy region of Italy, and to own a smartphone with Internet connection). Two exclusion criteria were added: being in the control group (who did not receive the app) and not having logged in the app during the experiment. Recruitment of the participants for the experiment was conducted through registered pediatricians and a marketing agency between April and November 2016. Data were collected between December 11<sup>th</sup>, 2016 and January 15<sup>th</sup>, 2017.

### 7.2.1.1 Measures

#### 7.2.1.1.1 Mobile App Rating Scale (MARS)

The Mobile App Rating Scale (MARS) is a 23-item scale developed to assess the quality of mobile health apps (Stoyanov et al., 2015). In previous studies, the scale showed high reliability (Domnich et al., 2016; Stoyanov et al., 2015). The MARS is composed by two subscales, one assessing four objective qualities (engagement, functionality, aesthetics, and information quality) and one assessing subjective qualities (Stoyanov et al., 2015). In addition, it provides 6 app-specific items measuring perceived outcomes to be adjusted to each health context (Stoyanov et al., 2015). The original scale was adapted to the context of our smartphone app and included 8 items assessing all four objective qualities mentioned above and two items assessing subjective qualities. The objective qualities included entertainment, interest, interactivity, ease of use, visual appeal, goals, quality of information and credibility. They were all measured with one item each, and response was recorded on a 5-point Likert scale measuring agreement and anchoring at “Absolutely agree” and “Absolutely disagree”. To measure the app’s subjective qualities we included a star rating question (with the possible scores ranging from one to 5 stars) and one question asking how likely the participant would recommend the app in the future (with answers ranging from “Very unlikely” to “Very likely” on a 5-point scale).

In addition, we included 3 items assessing participants’ perceived impact of the app on their knowledge (“MorbiQuiz has helped me deepen my knowledge of vaccination”), on their help seeking (“MorbiQuiz has increased my desire to collect information about vaccination”), and the perceived likelihood of actual change in the target health behavior (“After using MorbiQuiz, do you think that this app could change parents’ vaccination decision?”). Responses were recorded on a 5-point scale measuring agreement and anchoring at “Absolutely agree” and “Absolutely disagree” for the first two items, while they were measured on a 7-point scale ranging from “Yes, discouraging vaccination” to “Yes, favoring vaccination” for the third item. A mid-way option “I don’t think it can make a difference” was also provided.

The posttest questionnaire also assessed the experiment’s primary and secondary variables measured in the baseline survey (intention to vaccinate, confidence in the

decision, etc.), participants' social norms regarding the MMR vaccination decision, any problems that prevented regular access to the app during the experiment, and participants' online information seeking behaviors.

#### *7.2.1.1.2 Socio-demographic information*

We assessed a number of socio-demographic characteristics including gender, age, education, nationality, number of children, and ZIP code.

#### *7.2.1.2 Analyses*

Data analysis was performed using the Statistical Package for Social Science (SPSS; Version 21.0). ANOVAs were performed for each variable to determine whether there were differences among the experimental conditions. Where appropriate, planned contrasts were conducted to analyze significant differences across the experimental conditions.

### *7.2.2 Results*

#### *7.2.2.1 Participants' characteristics*

In total, 140 participants of the RCT answered questions related to the app's qualities. The majority of the participants had only one child ( $n=110$ ), were mothers ( $n=138$ ), and Italian nationals ( $n=136$ ). Participants' mean age was 33.96 ( $SD=5.52$ ,  $range=21-47$ ). About one third had completed secondary school ( $n=43$ ) while most had a university degree ( $n=84$ ). See Table 7 for participants' characteristics and Table 8 for their scores related to the app's qualities.

**Table 7.***Study 1 participants' characteristics*

	Experimental group		
	1 (n=48)	2 (n=45)	3 (n=47)
Gender			
Women	n= 43	n= 43	n= 46
Men	n= 5	n= 2	n= 1
Age	M= 33.44; SD= 4.27	M= 34.49; SD= 4.46	M= 33.98; SD= 4.86
Nationality			
Italian	n= 45	n=45	n= 46
Brazilian	-	-	n=1
Mexican	n=1	-	-
Moroccan	n=1	-	-
Education			
Middle School	n=3	-	n=1
University	n=23	n= 30	n= 31
Secondary School	n= 17	n= 13	n= 13
Apprentice	n= 4	n= 2	n= 2
No. of children			
1	n= 40	n= 35	n= 35
2 or more	n= 8	n= 10	n= 12

**Table 8.***Survey results per experimental group*

			Quiz n=48 (1)	Videos/ messages n=45 (2)	Quiz + Videos/ messages n=47 (3)	<i>F</i> ( <i>p</i> )	PostHoc Test
Engagement	Entertainment	Using MorbiQuiz was fun	M=4.63 (SD=.57)	M=3.87 (SD=.94)	M=4.62 (SD=.79)	$F(2,137)=14.248$ ; $p<.000$	13 2
	Interest	The contents of MorbiQuiz are presented in an interesting way	M=4.54 (SD=.74)	M=3.78 (SD=1.02)	M=4.45 (SD=.90)	$F(2,137)=9.97$ ; $p<.000$	13 2
	Interactivity	I felt as Sofia was talking to me	N/A	M=3.80 (SD=1.25)	M=3.72 (SD=1.19)	$F(1,90)=.09$ ; $p=.765$	N/A
Functionality	Ease of use	MorbiQuiz is easy to use	M=4.81 (SD=.44)	M=4.20 (SD=1.01)	M=4.70 (SD=.75)	$F(2,137)=8.35$ ; $p<.000$	13 2
Aesthetics	Visual Appeal	I like the graphics of MorbiQuiz	M=4.65 (SD=1.635)	M=4.07 (SD=1.03)	M=4.55 (SD=.829)	$F(2,137)=6.252$ ; $p=.003$	13 2
Information	Goals	It is easy to understand what MorbiQuiz is for	M=4.63 (SD=.61)	M=4.20 (SD=.84)	M=4.70 (SD=.55)	$F(2,137)=7.36$ ; $p=.001$	31 2
	Quality of information	MorbiQuiz's contents are easy to understand	M=4.56 (SD=.58)	M=4.40 (SD=.86)	M=4.36 (SD=.89)	$F(2,137)=.86$ ; $p=.423$	N/A

Subjective	Credibility	The contents of the quiz are reliable	M=4.5 (SD=.62)	N/A	M=4.49 (SD=.8)	$F(1,90)=.005$ ; $p=.942$	N/A	
		The contents of the videos are reliable	N/A	M=4.11 (SD=.86)	M=4.23 (SD=.96)	$F(1,90)=.42$ ; $p=.52$	N/A	
	Star rating	Star rating	M=4.5 (SD=.55)	M=3.76 (SD=.74)	M=4.23 (SD=.67)	$F(2,137)=15.335$ ; $p<.000$	13	2
		Future recommendation	M=4.27 (SD=.87)	M=3.91 (SD=.7)	M=4.38 (SD=.79)	$F(2,137)=4.419$ ; $p=.014$	3	2
App-specific	Awareness/ Knowledge	MorbiQuiz has helped me deepen my knowledge of vaccination	M=4.58 (SD=.58)	M=3.89 (SD=.88)	M=4.70 (SD=.72)	$F(2,137)=16.36$ ; $p<.000$	31	2
		Help seeking	M=4.42 (SD=.68)	M=4.09 (SD=.90)	M=4.34 (SD=.91)	$F(2,137)=1.93$ ; $p=.148$	N/A	
	Behavior change	After using MorbiQuiz, do you think that this app could change parents' vaccination decision?	-	-	-	-	-	

#### 7.2.2.2 Objective qualities

Participants' scores related to the app's objective qualities were, overall, high. We found, however, significant differences among the three experimental groups for a number of qualities assessed.

*Engagement.* We found significant differences among the three groups regarding entertainment ( $F(2,137)=14.248$ ;  $p<.000$ ) and interest ( $F(2,137)=9.97$ ;  $p<.000$ ). In particular, when we made a comparison between the groups receiving the knowledge and empowerment interventions, we found that participants who received the former were more likely to report that using MorbiQuiz was fun ( $M=4.63$ ;  $SD=.57$ ) and that the contents of MorbiQuiz were presented in an interesting way ( $M=4.53$ ;  $SD=.74$ ) compared to those who received the latter ( $M=3.87$ ;  $SD=.94$  and  $M=3.78$ ;  $SD=1.02$ ). To understand what gamification adds to the perception of the intervention employing the videos, we also compared the groups receiving the empowerment intervention only with those receiving the combined version. Those in the combined intervention group also scored significantly more on entertainment ( $M=4.62$ ;  $SD=.79$ ) and interest ( $M=4.45$ ;  $SD=.90$ ). Concerning interactivity, which indicates the perception that Sofia (the mother acting in the two videos) was directly addressing the participant, we found no statistical difference between the empowerment intervention only and the combined interventions groups ( $F(1,90)=.09$ ;  $p=.765$ ).

*Functionality.* The three experimental groups also significantly differed in their opinion on the extent to which MorbiQuiz is easy to use ( $F(2,137)=8.35$ ;  $p<.000$ ). Participants in the group receiving the knowledge intervention reported significantly higher ease of use of the app ( $M=4.81$ ;  $SD=.44$ ) compared to those who received the empowerment intervention ( $M=4.20$ ;  $SD=1.01$ ). When we compared the groups receiving the empowerment intervention only with those who received both intervention, we found that the former reported significantly higher ease of use of the app compared to the latter ( $M=4.70$ ;  $SD=.75$ ).

*Aesthetics.* The three groups also showed significant differences in their perceived visual appeal of MorbiQuiz ( $F(2,137)=6.252$ ;  $p=.003$ ). Participants in the group receiving the knowledge intervention only reported significantly higher appreciation of the graphics



of MorbiQuiz ( $M=4.65$ ;  $SD=1.635$ ) compared to those who received the empowerment intervention ( $M=4.07$ ;  $SD=1.03$ ). Participants in the group receiving the knowledge and empowerment interventions combined also reported significantly higher appreciation of the graphics of MorbiQuiz compared to those who received the empowerment intervention only ( $M=4.55$ ;  $SD=.829$ ).

*Information.* Regarding information, we found a statistical difference among experimental groups for goals ( $F(2,137)=7.36$ ;  $p=.001$ ), but not for the perceived quality ( $F(2,137)=.86$ ;  $p=.423$ ) and credibility of the information (contents of the quiz:  $F(1,90)=.005$ ;  $p=.942$ ; contents of the videos and messages:  $F(1,90)=.42$ ;  $p=.52$ ). In particular, participants in the groups receiving the knowledge intervention reported significantly higher ease in understanding the scope of MorbiQuiz ( $M=4.63$ ;  $SD=.61$ ) compared to those who received the empowerment intervention only ( $M=4.20$ ;  $SD=.84$ ). Those in the knowledge and empowerment interventions combined also reported significantly higher ease in understanding the scope of MorbiQuiz ( $M=4.70$ ;  $SD=.55$ ) compared to those who received the empowerment intervention only.

### 7.2.2.3 Subjective qualities

Similar to the objective qualities, the app received high scores for the subjective qualities, with significant differences between experimental groups. In terms of rating ( $F(2,137)=15.335$ ;  $p<.000$ ), the groups receiving the knowledge intervention only gave MorbiQuiz a significant higher number of stars ( $M=4.5$ ;  $SD=.55$ ) compared to those who received the empowerment intervention only ( $M=3.76$ ;  $SD=.74$ ). Likewise, those in the knowledge and empowerment interventions combined gave MorbiQuiz a significant higher number of stars ( $M=4.23$ ;  $SD=.67$ ) compared to those who received the empowerment intervention only.

In general, disregarding the experimental group, parents would recommend the app ( $M=4.19$ ;  $SD=.813$ ). There are, however, statistically significant differences according to the experimental group ( $F(2,137)=4.419$ ;  $p=.014$ ). Those in the combined version group reported the highest score ( $M=4.38$ ;  $SD=.79$ ), which is significantly higher than the group receiving the empowerment intervention only ( $M=3.91$ ;  $SD=.7$ ). The second highest

recommendation score is reported by those in the knowledge intervention only group ( $M=4.27$ ;  $SD=.87$ ).

#### 7.2.2.4 Perceived impact of the app

Regarding participants' perceived impact of the app on their knowledge, we found statistical differences among groups ( $F(2,137)=16.36$ ;  $p<.000$ ), with the combined interventions group reporting the highest impact ( $M=4.70$ ;  $SD=.72$ ), followed by the knowledge intervention group ( $M=4.58$ ;  $SD=.58$ ) and, finally, the empowerment intervention group ( $M=3.89$ ;  $SD=.88$ ). Regarding participants' perceived impact of the app on their information seeking behavior, the group receiving the knowledge and empowerment interventions combined reported the highest score ( $M=4.34$ ;  $SD=.91$ ) but we did not find any statistical differences between groups ( $F(2,137)=1.93$ ;  $p=.148$ ).

Regarding the participants' perceived likelihood of actual change in the vaccination behavior, only 1.4% of the participants reported that MorbiQuiz discourages vaccination, while 12.1% affirmed that it cannot make a difference (6 participants from the knowledge intervention group, 9 from the empowerment intervention group, and 2 from the combined interventions group). The large majority (86.5%) reported that the app could make parents opt for vaccination (41 from the knowledge intervention group, 35 from the empowerment intervention group, and 45 from the combined interventions group).

### 7.3 Study 2

#### 7.3.1 Methods

Study 2 is a qualitative study conducted with a subsample of the participants who took part in Study 1. Participants were recruited through the posttest questionnaire that followed the assessment of the experiment. To recruit participants, a final question was added to the questionnaire, asking whether we could contact the participant for a short telephone interview to share the experience with the app. A lottery was employed as an incentive to participation, with one shopping voucher worth 200 euros to be drawn. If participants

accepted to be contacted, they were asked to provide a telephone number. We sent a message to all telephone numbers provided, asking to suggest a suitable date and time when to conduct the interview. We developed a list of semi-structured interview questions aimed at exploring the perceptions and experiences of parents with regards to their use of the app (see Appendix 8). All questions were open-ended in order to facilitate our understanding of parents' experiences and feelings, as well as their suggestions and remarks. The interview grid was flexible in the sense that question order could be changed according to the flowing of the conversation. Consent to participate and to have the interview recorded was obtained prior to starting the interview. We recorded all interviews using a call recorder app and transcribed them verbatim.

Two coders independently performed an inductive thematic analysis of the transcripts (Braun & Clarke, 2006). Initially, the transcripts were read several times and openly coded manually, underlying meaningful parts. At a later stage, all codes were grouped under labels and organized hierarchically using a tree diagram. All labels were finally grouped under broader themes. During the whole process, telephone and face-to-face meetings between the two coders were regularly conducted to compare, discuss and refine the codes, labels, preliminary themes, and relative quotations. We conducted the interviews between December 19<sup>th</sup>, 2016 and January 13<sup>th</sup>, 2017. Both the transcription and the analysis of the interviews were conducted in the original language (Italian).

### *7.3.2 Results*

#### *7.3.2.1 Participants' characteristics*

In total, 115 participants accepted to participate in the telephone interview. Of these, 1 did not provide a telephone number. Of the 114 telephone numbers received, 39 participants did not suggest a date and time to be called. We called 75 participants, of which 15 never answered the call. The final sample (N=60) included 21 participants from the knowledge intervention group, 15 participants from the empowerment intervention group, and 24 participants from the combined knowledge and empowerment interventions group. Most participants were women (93%), in their early 30s ( $M = 33.78$ ), Italian nationals (99%),

and with one child (78%). See Table 9 for participants' characteristics. The themes extracted were grouped around those related to participants' experience with the quiz and those related to participants' experience with the videos and messages.

**Table 9.**

*Study 2 participants' characteristics*

	Experimental group (N=60)		
	1 (n=21)	2 (n=15)	3 (n=24)
Gender			
Women	n= 19	n= 14	n= 23
Men	n= 2	n= 1	n= 1
Age	M= 33.61 SD= 3.99	M= 34.4 SD= 5.22	M= 33.34 SD= 5.61
Nationality			
Italian	n= 21	n=15	n= 23
Brazilian	-	-	n=1
Education			
University	n=14	n= 8	n= 18
Secondary sc.	n= 6	n= 7	n= 5
Apprentice	n= 1	-	n= 1
No. of children			
1	n= 18	n= 12	n= 17
2 or more	n= 3	n= 3	n= 7

#### 7.3.2.2 General feedback

When asked about their general opinion of the app, participants spontaneously attributed a number of qualities to MorbiQuiz that covered a range of aspects, from its look to its contents. In general, participants defined the app useful, innovative and engaging, and described their experience as fun and pleasant. Most participants reported that MorbiQuiz was highly convenient, meaning that it is handy, quick, non-demanding, non-invasive,

easily accessible, and functional. They found the duration of the quiz a perfect match between a regular and gradual activity. Other remarks concerned its contents, defined as neutral/unbiased, complete, trustworthy, and rich. They also found the app simple, intuitive, clear, well structured, and captivating. Finally, participants described MorbiQuiz as highly educational and a useful tool that can help parents or soon-to-be parents to make a vaccination decision and stimulate one's information seeking. Participants' experiences with the app were grouped around four main themes, two related to the knowledge intervention and two related to the empowerment one.

#### *7.3.2.3 Experiences with the quiz*

When asked how the app helped them make a vaccination decision, participants in the knowledge intervention(s) felt that, after using MorbiQuiz, their decision was reinforced, they were more confident, more knowledgeable on the vaccination and had less fear of the side effects. The majority also complained that the app did not provide links to external resources after each quiz, which could have helped them enrich their knowledge further. To ensure that the app could be useful beyond the 10 days of quiz, about a quarter of the participants suggested to create a database containing all information provided by the quiz that is accessible and constantly update with news. About half of the participants suggested creating a similar app to inform parents about other vaccinations such as meningococcal vaccination.

##### *7.3.2.3.1 Learning from failure*

The large majority of the participants who received the knowledge intervention reported that a major quality of MorbiQuiz is that it offers a novel way of learning on vaccination compared to most traditional educational tools. Participants described their learning process through the app as an active one, whose main steps comprise receiving a question, seeking adequate information to answer appropriately, providing an answer and learning from the textual outcome of each answer.

*“I would receive a question and, often convinced of my answer which eventually would turn to be wrong, I would go and seek information on why I got it wrong. And thus.... In that sense, in my opinion, it helps increasing one’s knowledge.” (I1053, knowledge intervention)*

Most participants also stressed that MorbiQuiz invites to seek information actively and that it does so in a gamified way. They reported that this mechanism makes sure that either in case of correct or wrong answer, the participant has a chance to learn. In the first case, he or she will learn from the source consulted and from the textual content, while in the second case he or she will learn to question the information sources consulted and judge their credibility the following time, learning from the textual content.

*“It’s a call to play, it’s a call to act. It’s so interesting to me, when you open the first question, I mean, we have so many tools now to navigate online and find the right answer, don’t we? Indeed, it invites you.... To understand, read, analyze, right? Then you give your answer. If it’s right, fine. You are happy that what you had seen was correct, and you deepen your knowledge with the answer that you receive. If it’s wrong, then you start questioning the source that you had looked up, don’t you? This challenge needs to be stressed. This means putting yourself on the line, going to seek information, and finally getting active yourself.” (I1051, both interventions)*

Through the mechanism that provided a textual explanation after any right or wrong answers, most participants found that MorbiQuiz was effective in eliminating their doubts on the vaccination and in providing novel information.

*“[I was] not knowledgeable on the topic, I didn’t know... and answering, at the end of each answer it would say if the answer was correct or wrong, and it would provide an explanation to the question and those were really very... very useful,*

*because I had certain doubts and those have... they all have been practically removed.” (11097, knowledge intervention)*

*“The modality with the quiz followed by the explanation is undoubtedly very useful, because either in case of correct answer or wrong answer it offers anyway extra information compared to what you already know.” (11194, both interventions)*

Around half of the participants reported that the quiz also helped them improve their information seeking skills.

*“The quiz really enlightened me on aspects that... that I did not know, therefore some questions that I got wrong, it has really put me in the condition to better inform myself on those things that I really did not know.... In this sense it has made me more informed.” (11076, knowledge intervention)*

Participants appreciated the timeliness of the feedback they received from the quiz, indicating that, when they provided the answer, assessing their answer was quick and straightforward.

*“I have learnt many things, and this is the most important thing because even by making a mistake, there were anyway very clear explanations which gave you points of view... things that I absolutely didn’t know. Then it was very immediate as a thing... I mean rather simple the flow from questions to answers.” (11056, both interventions)*

#### 7.3.2.3.2 A challenge against oneself

When asked how they perceived the app’s leaderboard, the majority of the participants reported to have looked at it regularly during the quiz session. However, what emerges

from participants' reports is that the presence of the leaderboard does not correspond to a feeling of racing with others, but rather competing with oneself.

*"I simply played a game and, in this game, I collected information by receiving answers... Personally, I also like to race as a person, to confront myself... and... I mean, it was not a game against others. It was a game against myself." (11231, knowledge intervention)*

*"It has motivated me, I mean I asked myself... Am I the only one who gets them wrong? [laughs] I was interested in looking at it in the end because I made mistakes and then I would go and look for information on that." (11053, knowledge intervention)*

The majority of the participants found that the leaderboard added fun to the experience of collecting information and pushed to search more information to answer in a better way to the next questions.

*"I was a bit broken when I saw I was behind in the rank because I could not answer the questions... but it was fun, and the idea of the leaderboard was very stimulating." (11042, both interventions)*

*"It was fun because you would try to do your best possible. The leaderboard definitely acts as a... push. In a playful way, obviously." (11113, both interventions)*

Few participants reported to feel a sense of social support through the leaderboard, reporting a feeling of not being alone.



*“I think [the leaderboard] was... it was important that other parents have participated and have done the quiz... I felt... How to say... Not alone, that’s it.”*  
(11197, knowledge intervention)

#### 7.3.2.4 Experience with the video/messages

When asked how the app helped them make a vaccination decision, participants in the empowerment intervention(s) reported different general feedback. In particular, those exposed to both the quiz and the videos/messages felt that, after using MorbiQuiz, they had more confidence in their decision and knew more on the vaccination. Those participants in the empowerment intervention, on the contrary, were less convinced that the app had made an impact on their decision. In a similar fashion, when we elicited their feedback on the usefulness of the videos and messages, participants reported opposite views.

##### 7.3.2.4.1 A mother like me

Participants who received the videos and messages mainly reported comments on the videos, in particular the first one (the main and longest one). Around half of them found the video to be very close to their experience and pushing them to look for more information.

*“I found the video very clear, very close to me. The fact that the protagonist is a mother makes it even closer to the everyday life of us, mothers, rather than a more informative video, how to say, that would be colder, more detached.”* (11194, both interventions)

Participants found a similarity between the actress’ experience and their struggle to make a sound MMR vaccination decision for their children, reporting that the video appeared to be authentic and trustworthy.

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*“I felt it was really made by a... by a regular mother, not by someone... how to say... I mean by a mother like me! So I have to say, it was really nice... She would talk about the same problems that all mothers and fathers have when they have to choose.” (I1036, empowerment intervention)*

Few participants reported that they found a similarity between the decisional process described in the video and their decision-making process.

*“It felt like being... When I made the decision... like in this case, I mean I saw myself in this mother who gather information on the decision to vaccinate her child or not. I really liked that it was a real mother who talked. The character is trustworthy, it’s real, and authentic.” (I1051, both interventions)*

Some participants felt the video contained a direct message from a mother to another mother, while others felt like following the character’s story.

*“I interpreted it as a thought from a mother to a mother. I mean, a mother who tells you what she wanted to do with her child, and gives her advice as a mother to another mother.” (I1066, both interventions)*

*“It felt like following the story of this mother. It felt a bit like knowing her, like you were personally following her [...].” (I1109, both interventions)*

### 7.3.2.4.2 Need for direction

Around half of the participants declared that they found the video not useful, in the sense that it did not add anything to their knowledge nor stated the direction of the main character’s decision. As an alternative, they reported a preference for a video that would rather present information on the vaccination, possible side effects and main benefits.

*“The video does not provide information about the vaccination, it only tells about her that... [...] It does not provide information per se, I did not find it particularly useful. I don’t know why, I would have preferred a video with information, and then you use that information to answer the questions of the quiz.” (11238, both interventions)*

*“Maybe I was expecting that the mother would say in the end ‘this is what I chose’, maybe I was expecting this... I don’t know, it could be that we are used to see in the movies... to see a finale, but this mother was rather... rather cautious, she would say ‘I collected information before deciding’.” (11003, both interventions)*

Some parents suggested maintaining the narrative format, but replacing the mother with experts or different parents with contrasting opinions. In this sense, some clearly stated that they would not use a tool that is only made to invite them to seek information.

*“If the videos were present or not that would not have made any difference. Cause you could see this mother talking, telling her experience, but... But I think if there were more videos with, say, different opinions, from different mother, that would have maybe been more... more instructive, more of a general picture...” (11225, both interventions)*

*“I think it necessarily has to give some kind of information, beyond suggesting parents to seek information, I mean I cannot imagine an app that I simply access to hear “seek information, you have to look for information, yes, go and do it.” (11027, empowerment intervention)*

A small number of participants stressed the passive component of the videos, compared to the active characterization of the quiz.

*Honestly, I was not enthusiastic about the videos. They were kind of redundant. I found more answers and more stimuli in the quiz, maybe because when we are asked a question, it is up to us to answer and it sticks to our head for a longer time, as we think about it to find the correct answer... we think about it longer. But the videos, being a passive thing, did not make me enthusiastic.” (I1042, both interventions)*

#### 7.4 Discussion

The scope of this mixed-method study was to evaluate two interventions delivered through a smartphone app aimed at increasing parents' knowledge about the MMR vaccination and their empowerment in the MMR vaccination decision. Both interventions were previously tested in a randomized controlled trial. In particular, we were interested in capturing participants' opinion regarding a number of qualities of the app, such as usability and usefulness, and in acquiring information on their broader experience with the tool. A quantitative and qualitative study were conducted to reach these goals.

A first main finding springing from both studies is that overall participants perceived the app as highly usable and useful to make a vaccination decision. However, the results of the survey showed that the two groups receiving the quiz (alone or together with the videos/messages) liked the app significantly better compared to the group that only received the empowerment intervention through videos/messages. Furthermore, participants receiving only the quiz reported higher scores for most app's qualities compared to those receiving the videos/messages in addition to the quiz. Educational interventions are the most commonly cited interventions in the literature (Sadaf et al., 2013), which might signal that they are also the most common interventions parents are exposed to and which they are most acquainted with. This might explain why the educational version of the app received higher ratings. This is also the first immunization app in the Italian language with educational purposes, and the first attempt to empower parents about their vaccination decision through a mobile device (Chen et al., 2014; Katib et al., 2015; Panatto et al., 2016; Wilson, Atkinson, & Penney, 2015). Participants might

not be familiar with empowering interventions delivered through a video format and administered through an application for smartphone.

The results of the interviews also shed more light on between-group differences detected for the app's qualities, highlighting different experiences in relation to the type of intervention participants were exposed to. Parents' qualitative reports indicate that the knowledge intervention (employing the quiz and using elements of gamification) was perceived as an active learning experience, compared to the videos, which in turn were perceived as the passive exposure to a story. Furthermore, those in the knowledge group highlighted a number of positive aspects relative to learning, praising the gamified way by which they could not only acquire new information and question their previous knowledge but also improve their information seeking skills.

Parents receiving the empowerment intervention, on the other hand, lamented the lack of factual information that they would expect from a video, highlighting the emotional burden such a call for a self-determined decision might entail. The interviews' results also showed that mothers liked to identify themselves with the main character of the videos, as they share similar experiences and difficulties. However, beyond recognizing similarities with the protagonist, identification did not seem to be associated by parents with important aspects related to their decision-making regarding their child's MMR vaccination.

These results are in line with previous findings that interventions using gamification have the potential to increase engagement and intrinsic motivation (AlMarshedi, Wills, Wanick, & Ranchhod, 2014; Deterding, 2012; Lister, West, Cannon, Sax, & Brodegard, 2014). In particular, our study confirms previous findings that participation in gamified interventions was associated with users' engagement (Allam et al., 2015; Denny & Paul, 2013; Eickhoff et al., 2012.; Love et al., 2016), enjoyment of activities (Drace, 2013; Flatla et al., 2011; Li et al., 2012), increased task performance (Li et al., 2012; Hamari, 2013; Jung et al., 2010), higher empowerment (Allam et al., 2015), learning (Domínguez et al., 2013; El Tantawi et al., 2016; Hakulinen et al., 2013; Knight et al., 2010; Mokadam et al., 2015; Smith & Baker, 2011; Theng et al., 2015), and more positive attitude (Denny & Paul, 2013; Domínguez et al., 2013; Hamari & Koivisto, 2013). Our participants' reports that they felt more convinced of their vaccination decision after participating in the quiz

are also corroborated by a previous study that found gamification to be effective in reinforcing a behavior (Theng et al., 2015).

The findings of our evaluation study provide more explanation to the results of the previous RCT (Fadda et al., 2017), which found that only the group receiving the knowledge intervention significantly increased their intention to vaccinate against MMR and their confidence in making a vaccination decision. The results of the qualitative study can contribute to explain why we did not find a significant effect of the empowerment intervention on parents' vaccination intention and confidence. Parents need a clear direction or, at least, a comparison between different points of views on vaccinations. Excessively pressuring them to find vaccination-related information and to talk to different people – without providing factual information at the same time – might generate frustration and emotional distress. Indeed, different reviews of the evidence on the effectiveness of interventions aimed at increasing vaccination coverage point out that multicomponent interventions that have educational purposes should consider that the educational component alone might not determine large increase in vaccination acceptance, but could smooth the progress of implementation of other components (Briss et al., 2000; Dubé et al., 2015; Sadaf et al., 2013).

Finally, parents showed to be aware of the impact the app can have on their decision-making, with the large majority reporting it could potentially lead parents to opt for the vaccination. Users' awareness of the goal and the high potential of an application are crucial for making an app trustworthy and worth downloading or being recommended (Girardello & Michahelles, 2010; Kuehnhausen & Frost, 2013).

### **7.5 Limitations and conclusions**

While the studies showed to be successful in providing new insights into parents' perceptions of a novel immunization app, a number of limitations should be noted. A first limitation is that both studies' samples were mainly composed of pro-vaccination or

unsure parents. Acquiring the report of more vaccination-skeptical parents might have led to different results. A second limitation has to do with the incentives we offered to parents once the survey was completed. This might have played a role when parents reported their rating of the app, as they might have given higher scores in order to obtain the incentives we promised. Finally, social desirability biases may have occurred during the telephone interviews. Since the interviews were conducted by the team that developed the app, parents might have been led to report a positive experience to please the researchers.

This evaluation study showed to be useful not only to assess the two interventions beyond the results of the previous RCT where they were tested but also to understand participants' experience with the tool and contents they were exposed to and collect self-reported data on their perceived usability and usefulness of this instrument. The results can inform the design of future, similar interventions with educational or empowering purposes, suggesting that empowering efforts be always accompanied by the provision of factual information. Using a narrative format that allows identification can be appropriate, as it was reported to be associated with a feeling of social support that is called for by a recent taxonomy of communication interventions to improve routine childhood vaccination (Willis et al., 2013). This, however, should be employed together with the presentation of more points of views and notions regarding, for instance, the risks and benefits of the vaccination at the same time.

## **Chapter VIII**

### **Conclusion**

*Marta Fadda*



### **8.1 General summary of the findings**

Whether or not to vaccinate one's child is one of the first questions parents – and often soon-to-be parents – ask themselves when it comes to making decisions regarding the health of their offspring. Due to an increasingly large and contradictory amount of information available to them, not only through traditional channels, but also – and perhaps most importantly – through the Internet, such a question has become a dilemma for many parents (Betsch & Sachse, 2012). The intense and ubiquitous debate about the safety and efficacy of vaccinations – together with a number of widespread beliefs regarding, for instance, the supposedly unethical conduct of pharmaceutical companies and other conspiracy theories supported by anti-vaccination advocates – makes this decision a difficult one, and an increasing number of parents have decided to postpone the immunization of their children, or even reject it altogether (Diekema, 2012). Furthermore, the role of parents – just as much as that of patients – has dramatically changed over the past twenty years, and it is legitimate to assume that an increasing number of them might not want to straightforwardly follow the recommendations of their pediatrician or other medical professionals, but rather find information through other means and make an autonomous decision (Cooper et al., 2008).

Research has shown that, when faced with the decision to vaccinate their child or not, parents may feel overwhelmed by the plethora of contrasting information they are exposed to on vaccination (Fadda, Depping, et al., 2015; Fadda et al., 2016). Some of this information comes from the child's pediatrician or other health professionals, other from family members or other parents (peers), while an increasing amount is extracted by parents from the Internet and, in particular, from social media pages (Betsch, 2011). The latter source is possibly the most problematic one, considering the large quantity of anti-vaccination information offered online and the tactics used by its promoters (Kata, 2010, 2012). Furthermore, a recent finding that parents' previous vaccination knowledge does not affect their Internet searches suggest that they are indiscriminately subject to misinformation on vaccination (Kessler & Zillich, 2017). Recent studies have also pointed out the increasing number of medical professionals that are critical of vaccination (Bazán et al., 2017; Fortunato, Tafuri, Cozza, Martinelli, & Prato, 2015).

In this confusing and contradicting information environment, parents often rely on heuristics or shortcuts to make a vaccination decision (Ludolph, Allam, & Schulz, 2016; Wheelock, Miraldo, Parand, Vincent, & Sevdalis, 2014). Their emotions, beliefs, and (cultural) values come into play just as much as their previous experience with vaccination and diseases and, today more than ever, their preferences regarding the management of their child's health issues (Dubé et al., 2013; Wheelock, Parand, et al., 2014). Traditional theoretical models that seek to explain what differentiates parents deciding to immunize their child from those deciding not to do so (such as the Health Belief Model or the Theory of Reasoned Action) do not take into account parents' exposure to vaccination-related information and the changes that the current healthcare model has brought into the way that parents wish to manage their children's health.

This dissertation provides a novel way at looking at parents' vaccination decision-making, by means of applying a theoretical model that incorporates the construct of psychological empowerment right next to that of vaccination knowledge/literacy. As a matter of fact, the traditional assumption that by providing better vaccination-related information to parents they will be more likely to vaccinate their children, is overcome by the Health Empowerment Model (Schulz & Nakamoto, 2013), which considers both vaccination knowledge and psychological empowerment as two equally-important factors affecting parents' vaccination decision, which are in turn subject to what parents hear or read about vaccination, especially in online environments.

This thesis' makes a contribution on two main levels; one theoretical and one methodological. It: (a) offers insights on how parents interpret the construct of psychological empowerment in the context of their child's vaccination decision, presenting a novel, context-specific conceptualization of psychological empowerment; (b) provides a valid and reliable instrument for measuring psychological empowerment in this specific context; and (c) tests how far increasing parental vaccination knowledge and their psychological empowerment can ultimately boost key vaccination-related outcomes, such as their intention to vaccinate. The findings of the six studies support the importance of including the construct of psychological empowerment as a variable for

understanding parents' vaccination decision, together with that of vaccination knowledge.

Given the recent studies documenting the increasing presence of anti-vaccination advocates online (Kata, 2010, 2012; Ward et al., 2015) and supporting the empowering potentials of social media (Wilson & Keelan, 2013), this dissertation sets off by exploring communication in the online environments searched by parents when seeking information on vaccination or that they visit to report their experience with immunization, namely discussion forums. Employing a content analytical approach, Chapter II summarized users' reported information with a special focus on their preferred arguments and corresponding sources. The results of the cluster analysis demonstrated that anti-vaccination users are significantly more active than pro-vaccination users (posting as much as half of all material despite constituting a small percentage of all users), presenting a variety of different types of arguments to discredit immunization, and for the most part presenting such arguments as springing from their own experience or from media (by posting, for example, links to external websites). At the opposite end of the scale are the pro-vaccination users – who can be further distinguished among those that are safety-focused and general users – mainly cite health professionals and friends. The Chapter provided a picture of what a typical Internet user might come across when interested in the topic of vaccination. Considering that anti-vaccination users have the potential to spread inaccurate information quickly and in an efficient way – by using narratives, for example – and that such online discussion forums offer huge opportunities for empowering parents in their vaccination decision, the Chapter also discussed the implications of such a scenario for public health and health communication, urging the need to monitor such spaces (possibly with automated, faster systems), to intervene whenever inaccurate information is publicly shared, or to act in a preventive way by means of warning users of the possible fallacies they are likely to encounter.

While Chapter II sought to examine online discussions and focused on elements of vaccination literacy employing a quantitative approach, Chapters III and IV plunged in the Health Empowerment Model, employing a qualitative approach using individual interviews and focus groups, respectively. Chapter III focused on the two constructs of psychological empowerment and vaccination literacy, while Chapter IV, on the other

hand, was focused on the former construct. Both studies showed that parents' perceived knowledge and psychological empowerment are two important aspects in their decision-making regarding their child's MMR vaccination, though each chapter reached complementary results and proposed different implications. The results of Chapter III suggested that parents may misinterpret the non-compulsory nature of vaccination, taking it as a sign that immunization is no longer necessary and that they may give up their role as autonomous decision-makers if they feel they do not have the skills to make a vaccination decision. Furthermore, the chapter showed that parents consider the vaccination as having an impact not only on their child, but also on their family and the community, and that the pediatrician can be perceived as a source of motivation to actively engage in the decision. Major implications were discussed for parent-pediatrician communication, suggesting that pediatricians should act as motivators by providing clear, concise and tailored information, by explaining the reasons of the non-mandatory nature of vaccination, and by discussing the impact of the vaccination decision at the child, family and collective level.

On the other hand, Chapter IV showed that, for the majority of parents, the perception of being competent in making a vaccination decision is crucial to feeling that the final decision is truly self-determined. In this sense, vaccination competence was interpreted not only as having accurate factual information on the vaccination, but also as possessing a set of skills related to finding and assessing information. Furthermore, the chapter showed that parents are concerned with both legal and ethical aspects related to their freedom of choice on their child's vaccination, presenting contrasting views on whether it is right or not to be autonomous in such a choice. Finally, the results of the study highlight the importance of medical professionals as allies in the strive for empowerment. For a considerable number of participants, it is only by feeling that they are guided by a trusted professional that empowerment can be reached in this decision. The implications of the findings were discussed in relation to healthcare providers, who should avoid extreme interpretations of the empowerment construct (such as avoiding any recommendation), but rather promote active and guided information searches and shared-decision making with parents on the child's vaccination.

Based on the results from the qualitative studies, Chapter V sought to summarize parents' beliefs in relation to psychological empowerment to develop and validate a scale to measure such a construct efficiently within the context of the vaccination decision. The analysis of the psychometric properties of the Vaccination Psychological Empowerment Scale (VPES) resulted in a 4-item scale covering two main aspects of psychological empowerment, namely parents' perceived influence of one's personal and family experience with vaccination on the one hand, and their desire not to ask other parents about their experience with vaccination/their lack of interest in other parents' vaccination opinion on the other. The conceptualization of psychological empowerment in the vaccination decision within the Health Empowerment Model can thus be adjusted to become a two-dimensional construct. Considering that key vaccination-related variables, such as intention to vaccinate, were significantly and positively associated with the VPES score, the chapter suggested that promoting empowerment in the vaccination decision should be embraced as a target by both healthcare providers and public health institutions. Practical ways for doing this could be offering continuous support to parents, providing tailored information, and asking them for feedback about their children's immunization outcome in order to ensure a positive experience with the immunization. At the same time, considering that parents with a lower intention to vaccinate were more interested in their peers' opinion and experience with vaccination, institutions should pay attention to parents' social networks by monitoring them, presenting accurate information whenever it is needed and promoting safe information exchanges.

In order to establish a causal relationship between vaccination knowledge and psychological empowerment, on the one hand, and key vaccination-related outcomes, on the other, Chapter VI presented the development and results of a randomized controlled trial employing a smartphone app. Not only did the study represent the first attempt to test the efficacy of an app on the vaccination decision, but it also allowed – at the same time – to test the efficacy of gamification and narrative/interpersonal communication as boosters of knowledge and empowerment, respectively. The RCT demonstrated that the manipulation of vaccination knowledge and psychological empowerment was successful in generating significant increases in these two variables among participants in the study.

When the effects of the manipulation were tested on vaccination intention, confidence and future recommendation, however, only the experimental group receiving the knowledge intervention reported a significant positive improvement in intention and confidence. The major limitations of the study were addressed, which included an extreme operationalization of psychological empowerment as an invitation to search for information and make an autonomous and informed decision. Following our recommendation, participants could have been exposed to an information overload that might have led them to confusion and even more uncertainty about their decision.

Finally, the randomized controlled trial presented in Chapter VI was evaluated employing a mixed-method approach, with the aim of providing a deeper explanation to the findings of the RCT and obtaining insights into parents' experience with the smartphone app we developed. Chapter VII demonstrated that the evaluation – which used both a survey and individual telephone interviews – was successful in explaining the findings of the RCT. Quantitative results showed that parents receiving the quiz reported significant higher scores in their rating of the app compared to those who received the empowering material (videos/messages) alone. Furthermore, parents' qualitative reports confirmed that the participants preferred to be offered a clear direction and to be provided with different information and points of view, rather than simply being told to look for information and search for different sources. Empowering efforts alone are perceived as useless and excessively emotionally demanding. An additional element that demonstrates the benefits of the Health Empowerment Model: knowledge and empowerment are two sides of the same coin.

## **8.2 Limitations**

A number of limitations to the present dissertation need to be mentioned. A major theoretical limitation is that we decided to employ a theoretical model (the Health Empowerment Model) that only included a restricted number of variables, namely psychological empowerment, vaccination literacy, and information sources. It was on these three factors that we focused our enquiry. Integrating the model with other variables may have led to different results. Another limitation related to the theory is that the Health

Empowerment Model borrows the conceptualization of psychological empowerment from organizational literature, and we initially conceptualized psychological empowerment accordingly. Despite our efforts to build a valid and reliable instrument to measure psychological empowerment in the vaccination decision-making context, the studies that formed the development of our scale were rooted in Spreitzer's conceptualization of psychological empowerment. Choosing a different framework for defining psychological empowerment, at least initially, – e.g. Zimmerman's conceptualization – may have led to different conclusions.

This dissertation is not without methodological limitations. For organizational reasons, the randomized controlled trial presented in Chapter VI employs a scale to measure psychological empowerment that does not correspond to the one developed in the validation study presented in Chapter V. In a similar fashion, the way psychological empowerment was operationalized in the RCT does not match with the conceptualization of empowerment that derived from the validation study's results. While offering interesting points of departure for conducting future studies, this limitation may weaken the consistency between the RCT and the validation study and could represent a possible reason to ascribe a lack of a significant impact of the manipulation of empowerment on vaccination intention in the RCT.

Furthermore, the studies presented in this dissertation rely on the reports of parents of young children, most of whom have declared to be in favor of the MMR vaccination. A major limitation lies in the limited number of respondents who are against or unsure about this immunization. Including their opinion in our analyses may have resulted in different findings.

Finally, although we only included parents of children aged between 15 and 18 months (the age when the first dose of the MMR vaccination is recommended), possible recalling bias may have occurred that could have distorted parents' perception regarding the factors that influence their decision-making. We cannot exclude that their past experience with vaccination (e.g. with their older children) may have affected their reports.

### **8.3 Implications of the findings and suggestions for future research**

The findings presented in this dissertation have a number of implications at both theoretical and practical levels. From a theoretical point of view, this dissertation suggests that psychological empowerment in the vaccination context is different from empowerment in other health contexts, possibly because parents are asked to make a vaccination decision not for themselves, but for their child. Issues of responsibility and anticipated regret are at stake. Rather than appearing as a four-dimensional construct constituted by perceived competence, meaningfulness, self-determination and impact, it seems that empowerment in the vaccination decision has more to do with the dimension of self-determination. What counts as empowerment seems to be the perception that one's own or family experience is what guides the decision, as well as not being interested in what other parents think or have experienced with regard to vaccination. This novel conceptualization implies that the Health Empowerment Model ought to be revisited and refined accordingly within the context of such decision-making.

The results of the studies presented in this dissertation can also influence public health policy. In particular, it emerged that issues of psychological empowerment, which play an important role in the decision whether to vaccinate one's child or not, are often neglected by public health institutions. Our findings suggest that vaccination policy should disclose the reasons why vaccinations are (not) mandatory, as this is often interpreted by parents as a signal that vaccinations are not useful, efficient or safe. Also, empowering strategies should be adopted by public health institutions to reinforce parents' self-efficacy and self-determination. As the results of the RCT presented in Chapter VI pointed out, it is only by offering the proper information and empowering parents at the same time, that the highest knowledge gain can be obtained. Thus, educational efforts should be integrated with an empowering component.

The findings of this dissertation can also influence future communicative efforts that are aimed at boosting vaccination coverage. Messages directed to parents should take into account empowerment and knowledge at the same time to obtain more educational success. In addition, this thesis has demonstrated that digital interventions can be effective in increasing vaccine acceptance. Offering digital information rather than information via



paper or traditional media can help overcome the challenge of maintaining public confidence in vaccines.

Finally, pediatricians and other healthcare providers were consistently cited as the main information source by parents across our studies. While it should be noted that they are increasingly under pressure to see more patients in less time, it should also be stressed that they have huge potential for guiding the parents exposed to inaccurate and poor vaccination-related information through the Internet or other sources. Our results should encourage them to find effective ways to communicate accurate and objective information to parents about vaccines and to address their specific concerns in a way that parents can process, suggesting possible sources and offering the tools to recognize reliable information (Fredrickson et al., 2004; Kempe et al., 2011; Siddiqui et al., 2013). At the same time, they should engage parents in the vaccination decision, promote their active information-seeking, elicit questions and ensure a positive experience with all matters concerning the vaccination decision.

The construct of psychological empowerment in the vaccination decision deserves further attention and there is still undoubtedly a long way to go. This dissertation is promising, in that it suggests possible routes to take in the study of such a construct. In line with the implications, further research should test whether increasing parents' psychological empowerment according to the conceptualization emerging from our validation study (Chapter V), together with their knowledge of vaccination, will lead to higher intention to vaccinate. This could be done by highlighting the importance of one's own experience and family's history with vaccinations on the immunization decision, or by warning against the possible inaccurate information parents can obtain comparing themselves with their peers.

Our studies reinforce the importance of recognizing the construct of psychological empowerment as a factor affecting vaccine hesitancy, whose integration into existing and future frameworks could benefit our understanding of the phenomenon.

## *Chapter VIII*

Future studies could apply the Health Empowerment Model and integrate it with other variables in different settings to widen its applicability.

## **Ethical considerations**

All studies presented in this dissertation underwent ethical review by an independent ethical committee.

### **Chapter II**

The study did not require ethical approval, as stated by the Ethics Committee of the Canton of Ticino on March 10<sup>th</sup> 2014, since data were anonymous and the study did not entail recruiting subjects. However, we obtained the hosts' permission to retrieve and analyze data from the forums for research purposes.

### **Chapter III**

The study was approved by the Ethics Committee of the Canton of Ticino on March 4<sup>th</sup>, 2014 (Rif. CE 2770).

### **Chapter IV**

The study was approved by the Ethics Committee for Clinical Trials of the Province of Trento on November 27<sup>th</sup>, 2014 (ID 54896583).

### **Chapter V**

The study was approved by the Ethics Committee of the University of Milan on June 3<sup>rd</sup>, 2015 (decision no. 32/15).

### **Chapters VI and VII**

The studies were approved by the Ethics Committee of the University of Milan on April 18<sup>th</sup>, 2016 (decision no. 14/16).

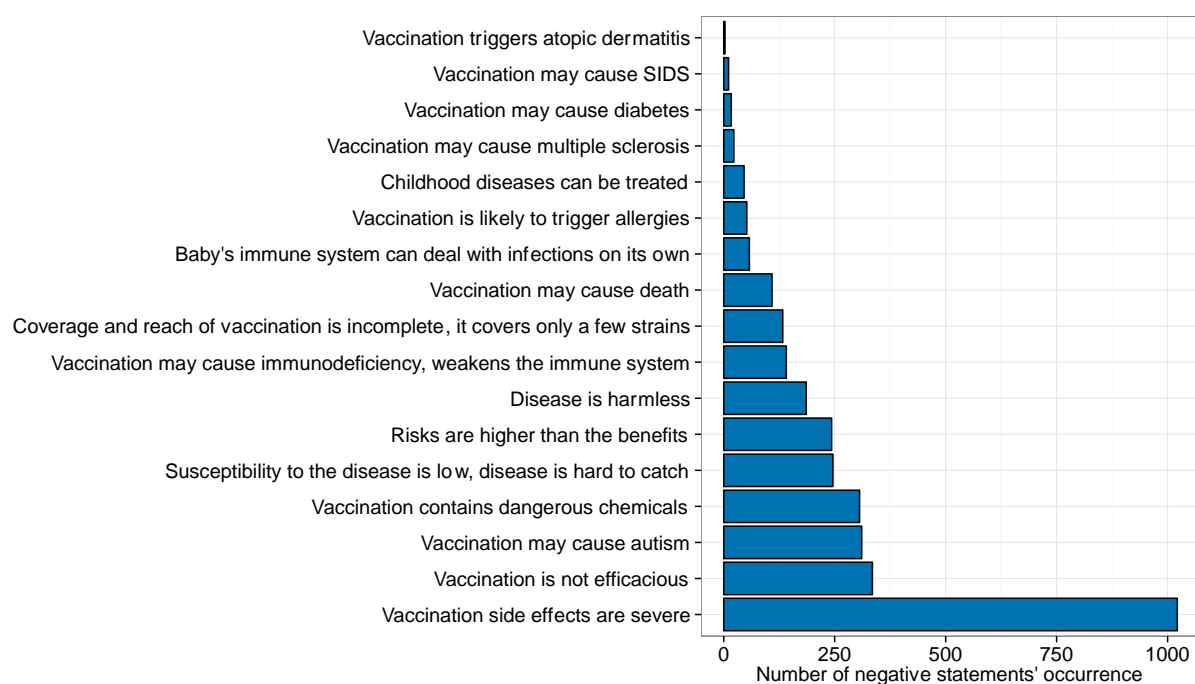
## Appendix 1

Inter-rater reliability of the coded variables computed using Fleiss' Kappa

Variables		Pilot reliability	Mid-term reliability
		$\kappa$	$\kappa$
F1	Forum's name	1.00	1.00
F2	Foum's number	1.00	1.00
F3	Number of posts	1.00	1.00
F4	Post ID	1.00	1.00
F5	Date of publication	1.00	1.00
F6	Time of publication	1.00	1.00
F7	Author's nickname	1.00	1.00
C1	Author's gender	0.57	0.87
C2	Main content	0.82	0.78
C3	Level of concern	0.80	1.00
C4	Need for information	0.62	1.00
C5	Main vaccination discussed	0.74	0.75
C6	Argument on vaccination	0.68	0.72
C7	Source of argument	0.63	0.85
C8	Recommendation	0.48	0.72
C9	Author's position	0.71	0.77

## Appendix 2

### Distribution of negative statements



## Appendix 3

### Tables 1 and 2

**Table 1.**

*Aggregated counts (un-normalized values) of posted argument types and corresponding position toward pediatric vaccines for all users belonging to each cluster*

Argument type X Position	Anti-vaccination	General pro-vaccination	Safety-focused pro-vaccination
Safety of vaccination			
Low	1598	104	65
High	178	205	511
Efficacy of vaccination			
Low	409	93	24
High	68	298	52
Disease severity & susceptibility			
Low	284	94	13
High	97	577	51
Benefits vs. risks of vaccination			
Risks are higher	192	24	6
Benefits are higher	71	181	59

**Table 2.**

*Aggregated counts (un-normalized values) of cited sources for posted arguments for all users belonging to each cluster*

Cited source type	Experiential	Multi-source	Medical-dependent	Media-fans
Own experience	959	250	75	68
Relative or friend	41	83	7	9
Friend of friend/relative	12	19	2	4
Facebook/other social network contact	2	29	3	5
Doctor/other medical professional	84	100	276	25
Anti-vaccination activist	2	31	2	0
CAM professional	0	4	2	0
Book	5	54	3	23
Teacher	0	0	1	0
Media	61	87	26	486
Rumors	45	208	15	9

## Appendix 4

### Interview schedule

Interview topics and sub-topics	Key interview questions
Confidence in one's MMR vaccination decision	How confident are you in your decision about the MMR vaccination for your child?
Vaccination literacy	
General beliefs	What do you think of the MMR vaccination?
Procedural knowledge	When is MMR due for your child?
Subjective knowledge	Do you feel sufficiently informed about the MMR vaccination?
Perceived outcomes of MMR	What comes to your mind when you think of the positive outcomes of the MMR vaccination? What comes to your mind when you think of the negative outcomes of the MMR vaccination?
Information seeking behaviors	Which sources did you use? Which sources have contributed most to your decision-making?
Empowerment	
Meaningfulness	What are the major decisions that you have made for your child so far? How important is your choice about the MMR vaccination compared to other decisions made for your child so far?
Self-efficacy	What makes one able to make a sound decision about MMR? What skills would one need to have in order to feel able? What does one need to know?
Self-determination	In your opinion, what does it mean to be autonomous in making a decision regarding MMR?
Impact	Under which circumstances would you feel that your decision regarding MMR did make a difference?



Social influences	Have you talked about the MMR vaccination with someone? Where and with whom? What have you been told?
Reactions to MMR-related information	Think of the last time you came across information on the MMR vaccination. Was there any information that made you particularly scared? Was there any information that made you particularly secure and relieved?
CAM usage	Do you use complementary or alternative medicines (CAM)? What comes to your mind when you think of CAM and measles?
Perceived risk of MMR and measles	What comes to your mind when you think of the probability that your child will contract measles? What comes to your mind when you think of its severity? What comes to your mind when you think of the probability that your child will have MMR side effects? What comes to your mind when you think of their severity?
Barriers to the decision	Was there anything that frustrated you during your decision-making?

## Appendix 5

### Interview schedule

Interview topics	Key interview questions
General health-related decision-making	What do you usually do when you have to make a decision concerning your own health? Why?
Child's health-related decision-making	Now think about the last time you had to make a health-related decision for your child. What did you do? Why?
MMR vaccination decision-making	How are you making a decision regarding your child's MMR vaccination? What are you taking into consideration? How do you feel about making this decision? Which experiences are helping or hindering you in making this decision?
Meaningfulness	What are the major decisions that you have made for your child so far? How important is your choice about the MMR vaccination compared to other decisions made for your child so far? Why is it more or less important than others are? What makes it important?
Autonomy	In your opinion, what does it mean to be autonomous in making an MMR vaccination decision for your child? Is it important to be autonomous?

Competence	<p>What makes one able to make a sound decision about MMR?</p> <p>Think of a competent parent who makes a sound MMR decision. Which skills does he or she have?</p> <p>What skills would one need to have in order to feel able?</p> <p>What does one need to know?</p> <p>Can you mention three skills that one needs to have to be competent?</p> <p>What is important for you to know right now?</p>
Shared decision-making	<p>Think of the meeting with the pediatrician when the topic of childhood vaccinations is discussed for the first time. How should it happen, in an ideal world?</p> <p>How did it take place, in your case (if any)?</p>
Gender roles	<p>How do you and your partner share the MMR vaccination decision, if you do?</p>
Reasons for participation	<p>Why did you decide to participate in this study?</p>

## Appendix 6

### The original 9-item Vaccination Psychological Empowerment Scale

Component	Item
Self-determination	I am the only one responsible for the consequences of my decision about my child's vaccinations
	My family's experience with childhood vaccinations has an influence on my decision about my child's vaccinations
	My decision about my child's vaccinations is especially driven by my personal experiences with vaccinations and diseases
Perceived competence	Hearing or reading information about childhood vaccinations from multiple sources makes it harder for me to decide
	When I face contradictory information about my child's vaccinations, I can recognize which part is correct and which is not
Perceived impact	The decision about my child's vaccinations will positively or negatively affect his/her social life
Perceived meaningfulness	I dedicate time and resources to decide whether to vaccinate my child or not
Information orientation	I am interested in what other parents think about childhood vaccinations
	I like to ask other parents about their experience with their children's vaccinations

## Appendix 7

### Cugelman's principles of gamification and techniques related to them

Principle	Technique used to implement the principle
1. Goal setting: Committing to achieve a goal	The goal to become more informed is highlighted by the use of a daily quiz that allows for active learning.
2. Capacity to overcome challenges: Growth, learning, and development	A personalized trajectory simulating growth is given in the main screen, where users can also display their time management (midnight deadline for each quiz).
3. Providing feedback on performance: Receiving constant feedback through the experience	Users are informed whether they gave a correct or wrong answer. A textual content is unblocked after each answer providing more information on the topic of the quiz.
4. Reinforcement: Gaining rewards, avoiding punishments	Users receive points for correct answers, while no points for ungiven or wrong answers. A monetary voucher is offered as a reward according to the final score obtained in the quiz.
5. Compare progress: Monitoring progress with self and others	Leaderboard where users can compare their score with that of other participants
6. Social connectivity: Interacting with other people	N/A for experimental control purposes
7. Fun and playfulness: Paying out an alternative reality	The quiz simulates parents' information-seeking in the real life but provides at the same time a fun experience made of rewards upon successful learning.

## Appendix 8

### Interview schedule

Interview topic	Key interview questions
General impressions	<p>What do you think of MorbiQuiz? What was your experience with this app?</p> <p>Is there anything about MorbiQuiz that you liked particularly?</p> <p>Anything that you did not like? Anything that annoyed you?</p>
Perceived effects	<p>What has changed in you after using MorbiQuiz? What was the effect of MorbiQuiz on you, if any?</p> <p>To what extent has MorbiQuiz helped you make an MMR vaccination decision for your child?</p> <p>What effects can MorbiQuiz have on other parents?</p> <p>Why should parents download and use MorbiQuiz?</p>
Quiz and gamification	<p>To what extent has the quiz helped you improve your knowledge about the MMR vaccination?</p> <p>What do you need to feel more knowledgeable?</p> <p>How did you perceive the leaderboard?</p>
Videos, messages and interpersonal communication	<p>What feelings did you have after watching the video? Which thoughts came to your mind after watching the video? How did you feel about receiving Sofia's messages?</p> <p>In your opinion, what is the take-home message of the video?</p> <p>To what extent videos and messages helped you feel more empowered in your decision?</p> <p>What do you need to feel more empowered?</p>

Suggestions

How would you improve MorbiQuiz?

Which features would you add/remove?

How would you see MorbiQuiz in the future?

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