

# Vaccine Distrust: Investigation of the Views and Attitudes of Parents in Regard to Vaccination of Their Children

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Défiance vaccinale : enquête sur les ressentis et croyances des parents autour de la vaccination de leurs enfants

Vaccine distrust: investigation of the views and attitudes of parents in regard to vaccination of their children

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#### TITRE COURANT: Vaccines: parents' views and attitudes

#### 1 Abstract

2 Background: In France, many parents have lost confidence in vaccinations, which has a direct impact on 3 immunization coverage. Pharmacists, like other health professionals, often encounter parents exhibiting vaccine 4 distrust. Methods: Using a survey distributed in a school and in a number of volunteering pharmacies, the 5 objective of this study was to gain a better understanding of the views and the attitude of parents in regard to 6 vaccination of their children. Results: Our results show that the main concerns were in regard to vaccine 7 adjuvants, the risk of short- and long-term adverse effects, and the risk of developing a disease or a disability as a 8 result of vaccination. The parents, although they tended to express a degree of reluctance and apprehension, in 9 general, they were not opposed to vaccination, and they sought objective scientific information and full 10 transparency regarding all aspects of vaccine composition, adverse effects, and effectiveness. Cooperation of all 11 the parties involved in the health system on this subject is essential for a seamless chain of care and to improve 12 vaccination coverage. Conclusion: The information collected, combined with a review of the international 13 literature, allow avenues for dialogue adapted to parents' opinions to be established and thus assist health 14 professionals to communicate effectively regarding vaccines, which is a bona fide public health issue.

15 Keywords: Immunization coverage. Parents. Pharmacists. Vaccines. Vaccination refusal

#### 16 Résumé

17 Position du problème : En France, de nombreux parents perdent confiance en la vaccination, ce qui impacte 18 directement la couverture vaccinale. Les pharmaciens d'officine, comme les autres professionnels de santé, sont 19 souvent confrontés à des parents montrant une défiance vaccinale. Méthodes : A l'aide d'une enquête diffusée 20 dans une école et au sein de pharmacies d'officine volontaires, l'objectif de cette étude était de mieux 21 comprendre le ressenti et les croyances des parents autour de la vaccination de leurs enfants. Résultats : Les 22 résultats montrent que les principales craintes concernaient les adjuvants vaccinaux, le risque d'effets 23 indésirables à court et à long terme ou encore le risque de développer une maladie ou un handicap après la 24 vaccination. Les parents, pour la plupart hésitants ou méfiants et non pas opposés à la vaccination, étaient 25 demandeurs d'informations scientifiques objectives et d'une transparence parfaite sur tout ce qui concerne la 26 composition des vaccins, leurs effets indésirables et leur efficacité. La coopération de tous les acteurs du système 27 de santé sur le sujet est primordiale pour assurer un maillage complet dans la chaîne de soins et améliorer la 28 couverture vaccinale. Conclusion : Les informations collectées, associées à une revue de la littérature

- 29 internationale, permettent d'établir des pistes de dialogue adaptées aux opinions des parents et d'aider ainsi les
- 30 professionnels de santé à communiquer sur les vaccins, véritable enjeu de santé publique.
- 31 Keywords: Couverture vaccinale. Hésitation vaccinale. Parent. Pharmacien. Vaccin
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#### 34 Introduction

35 Morbidity and infant mortality have decreased considerably with the progression of rudimentary immunizations 36 to widespread use of modern vaccines. Indeed, the World Health Organisation estimates that 2 to 3 million 37 human lives are saved each year through vaccination (1). However, there is a growing distrust of vaccination and 38 this is in fact now becoming a serious public health issue in most industrialised countries. According to the results 39 of the Vaccine Confidence Project (2), France has the highest rate of vaccine distrust, with no less than 41% of 40 people having doubts regarding the safety of vaccines and only 75% having favourable opinion of vaccination. 41 Since vaccination is a major public health issue that affects child health, there is ample reason to examine parents' 42 representations and fears regarding vaccination of their children. In France, pharmacists are increasingly involved 43 in public health measures, including immunizations. The purpose of this study was, through use of a survey, to 44 understand the mechanisms involved in vaccine mistrust and to assess the trust parents have in their pharmacist 45 for vaccination. Using these results and previous research on the subject, we present a tool for assisting health 46 professionals to communicate with parents regarding their views on vaccination.

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#### 49 Methodology

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The survey consisted of 17 questions divided into 5 sections. It provided three free-expression fields. The questionnaire, in paper format and accompanied by an information sheet, was provided to parents at multiple locations in the Pays de la Loire region (in western France), according to two distinct methods:

- distribution to children at school (nursery school and public primary school) so that they could give it to their

parents when they got home. The parents could return the completed questionnaire to their child or directly to

the teachers who then forwarded them to us.

57 - distribution directly to the parents as part of their child's vaccination process at various volunteering pharmacies

58 throughout the city of Nantes.

59 The prerequisites for being included in the study were being a parent of one or more children from 0 to 18 years

60 of age and having an adequate level of understanding of the French language.

61 In all cases, the questionnaire was completed by the parents at home, knowing that they had the choice to return

- 62 it or not to the school or the pharmacy.
- 63

64 The survey was anonymous and voluntary. Prior to its diffusion, the survey was developed by a multidisciplinary

65 collaboration involving hospital pharmacists specialized in public health, a referring physician from a vaccination

66 center, and a biostatistician.

67

68 Several themes were selected to be addressed in the survey:

69 First, general information about the person who completed the questionnaire: parental status and number,

70 gender, and age of their child(ren). This category allowed to verify that the inclusion criteria were met and to

71 collect various relevant details regarding the participants.

72 The immunization status of the child(ren) was then requested. The parent was questioned on their knowledge of 73 diseases that are subject to mandatory vaccine prevention in France, and regarding the vaccination status of their 74 child(ren) in terms of mandatory and recommended vaccinations.

75 Part 3, "You and Vaccination", was the core element of the survey. Based on a global review of the literature and 76 in particular on the Australian Leask team survey (3), question to better define the opinion of the person 77 regarding vaccination was developed: convinced, somewhat apprehensive, reluctant, or opposed to it. Each 78 category was associated with an affirmation corresponding to a description of the feeling (for example 79 "vaccination scares me and I am reluctant to vaccinate my child"), the person being asked to choose the one best 80 matched their status. Categories 2 and 3 of the Australian study, which we deemed to be very similar, were 81 merged in our survey into a single category ("Somewhat apprehensive") to facilitate understanding by the 82 parents. The "Reluctant" classification thus accounting for category 4 of the Australian study - namely the 83 "selective vaccinators or latecomers". We then added several questions to determine the main sources of 84 information of the parents regarding vaccination and the elements that warranted improvement in regard to 85 communication about vaccines.

The person's perception of vaccines was evaluated: their level of confidence (from 0 to 10) regarding the most widely used vaccines (i.e., Diphtheria Tetanus Poliomyelitis (DTP), Measles Mumps Rubella (MMR), Hepatitis B, Meningitis, and Human Papillomavirus (HPV)) and whether the children had been vaccinated or not for each valence. The last question in this section was open and very broad, dealing with fears about vaccination. The answers were categorized and counted: at each evocation of one of the categories, 1 point was attributed to it in

91 order to weight the information obtained and to assign a growing order of the parents' fear of vaccination.

92 The 4<sup>th</sup> section entitled "You and your pharmacist", was intended to assess the level of confidence of the

93 respondents in their pharmacist about the information they can deliver about vaccination (on a scale of 0 to 10),

94 and to gauge the opinion of the parents on various possible engagements of the pharmacist for vaccination: the

95 establishment of a specific pharmaceutical interview, the possibility of reminding the person of their next

96 vaccination appointment, or the option to be vaccinated directly by the pharmacist.

97 The last section corresponded to a free-expression part: the interviewee could then raise subjects that seemed
98 necessary to them to explain or complete their answers by providing further details for example.

99 Informed consent was obtained from all the patients. The modalities for the collection of data were approved by

100 the ethics committee of the CHU (Nantes Ethics Group in the Area of Health, GNEDS).

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#### 104 Results

105 Ninety six people were included in the study (83 at the school and 13 through the pharmacies). The response rate 106 for the surveys distributed at the school was approximately 45% (83 responses out of the 186 distributed 107 questionnaires). The questionnaire was usually completed by the child's mother (91.67% vs 8.33% by the father). 108 It involved a total of 194 children (87 girls and 107 boys), with an average of 2.02 children per family. The average

age of the children was 7.4 years (standard deviation of 4.7 years).

recommended by the health agencies at the time of the survey.

In terms of the parents' awareness of the French vaccination requirements, nearly 98% of the parents knew that DTP vaccination was mandatory. They were a lot less sure of the recommended vaccinations: 61% of the parents thought that MMR vaccination was mandatory, 49% for pertussis, whereas these vaccines were, in fact, only

Assessing the parents' awareness of the immunization status of their children, we noted that 100% of the parents thought that their children were up to date with their mandatory vaccinations, even among those who were not in favour of vaccination. By contrast, only 73% of the parents thought that their children were up to date with the

117 recommended vaccinations.

118

119 The purpose of the "You and Vaccination ..." section, was to evaluate the parents' opinion on the subject. The

120 results are detailed below with the following proportions for the affirmation "In terms of vaccination, you are ...":

121 - Convinced: 40.66%

- Somewhat apprehensive: 50.00%
- 123 Reluctant: 7.29%
- 124 Opposed: 2.08%.
- 125

126 The two mains sources of information regarding immunization were health professionals and official websites,

127 although nearly one in six parents referred to unofficial websites or people they knew (Figure 1).

128 The level of satisfaction of the parents with the information they could obtain was mixed. Indeed, while nearly

129 34% of the respondents felt completely satisfied, the majority (44%) were only partially satisfied. Almost 12.5%

did not feel satisfied ("Not really" + "No, not at all"). Excluding people who did not answer this question (9%), and

131 combining the people who were not generally satisfied, we found that about 2/3 of the parents were not fully

132 satisfied with the information regarding vaccination.

133 The reasons provided by some in the free expression part for this dissatisfaction related to a variety of problems 134 that they encountered. What stood out most was the feeling of having information on the subject being hidden 135 from them (n=5). This was followed to equal extents by difficulty with finding objective information (n=4), the 136 contrast between information from official sites and anti-vaccine websites (n=4), and the degree to which the 137 issue is skewed as a result of lobbying by pharmaceutical companies (n=4). Their choices were also influenced by 138 problems stemming from the lack of availability of vaccines (n=3) and the contradictory information from 139 different health professionals (n=3). Finally, some parents mentioned difficulties understanding the medical 140 jargon (n=1).

141

142To better understand vaccine distrust, we asked the parents about their level of confidence in regard to the major143vaccines in France (Figure 2). Two vaccines in particular (namely MMR and DTP) inspired considerable confidence

144 (a rate > 8) while others were associated with lower levels of confidence, like HPV and Hepatitis B vaccines.

145

146 The children's vaccination coverage rates according to the parents were higher than 80% for DTP and MMR, but

147 lower for Hepatitis B and meningitis (Figure 3). Of 38 girls aged 11 or over, 31.6% had been vaccinated against

148 HPV.

149 In terms of the parents' fears about vaccination, adjuvants, side effects and disabilities due to vaccine were the 150 most cited (Figure 4). The "Other" category was subdivided as follows: Doctor against immunization (4.5%), 151 withdrawal of vaccine lots (4.5%), Vaccine risk higher than risk of contracting the disease (4.5%), lack of 152 consideration of the patient's background (2.3%) and anti-vaccine petitions (2.3%).

153 Regarding the parents' level of confidence in their pharmacist's advice about vaccination (from 0 = "not at all

154 confident" to 10 = "entirely confident"), the average score obtained was 6.84/10 (standard deviation of 2.7/10).

Half the participants agree meeting their pharmacist to discuss vaccination, but only a third would allowpharmacists to vaccinate patients (Table 1).

Being notified for upcoming appointments by e-mail was preferred (31.25%) over the use of text message (20.83%) or postal service (12.50%). Furthermore, 18.75% of the parents agreed to be reminded during a visit to the pharmacy.

160 In the free-expression category, 21.9% of respondents expressed an opinion. Several of the parents raised issues 161 regarding the questions that were asked, or they elaborated on their answers. Some parents expressed their 162 distrust of pharmaceutical companies and noted their feeling of sometimes being judged by health professionals 163 when they expressed doubts about vaccination. Finally, some participants came up with ideas for improving 164 immunization coverage and vaccine acceptability by the general public.

165

#### 166 Discussion

167 In order to collect as much information as possible from parents without introducing a bias by suggesting answers 168 that they would not have thought of spontaneously, the survey provided three free-expression fields. One of 169 these, regarding fears and representations about vaccination, was a deliberate choice to obtain a high diversity of 170 answers and especially not to skew the results by a list of predefined elements, which would have been 171 counterproductive given our objectives.

172 In terms of vaccination coverage rates for different diseases, the declarative data obtained with our questionnaire

are comparable to those of Public Health France 2014 (4).

174 The statistical power of our questionnaire would be obviously improved by a greater number of responses and a

175 greater geographical diversity of its dissemination. Nevertheless, it appears that the results that we obtained are

176 comparable to those of the national and international literature. In 2016, a 67-country survey conducted by the Vaccine Confidence Project found that the European region had lower confidence in the safety of vaccines than 177 178 other world regions (5). Moreover, the European region accounted for seven of the ten countries with the lowest 179 levels of safety-based confidence issues, four of which (France, Greece, Slovenia, and Italy) are in the European 180 Union (EU). Vaccine refusal has been increasing in many EU member states: between 2000 and 2017, routine 181 immunisation coverage of the first dose of a measles-containing vaccine has decreased in nine EU member states 182 and since 2010, it has increased to 12. In 2017, the number of confirmed measles cases was at their highest levels 183 since 2010. Of the 9,420 cases recorded in 2010, 86% were recorded in France, Greece, Italy, Romania, or the UK, 184 countries whose first-dose measles immunisation rates are below the threshold required to achieve herd 185 immunity (93-95%) (6).

186

187 In the section "You and vaccination ...", which seeks to evaluate the parents' opinion on the subject, the results
188 obtained are consistent with those of an Australian study in 2012 (3).

189 The French parents in our sample were broadly distributed in the same proportions as the Australian parents. 190 Nearly 60% of the parents exhibited a degree of mistrust of vaccination. This figure is above the 41% 191 disagreement in France with the notion that "overall, vaccines are safe" determined by the Vaccine Confidence 192 Project 2016 (2). These results are weighted by the fact that the parents who responded to the optional survey 193 are more likely to have had doubts in regard to immunization than the general population. Indeed, this bias is 194 known in marketing and can be applied to any study based on volunteering. Respondents who suffered a bad 195 interaction are more likely to share it on social media, online reviews or in surveys than those who had good 196 experiences. That's particularly problematic when the majority of respondents who have read negative reviews 197 claims that the information impacted their future decision. Hence, it is reasonable to assume that in vaccination 198 surveys, the proportion of people with a negative opinion will be higher than in the general population, and that 199 they will contribute to the spread of reluctance to be vaccinated. It should also be considered that the Vaccine 200 Confidence Project was only concerned with the safety aspect of vaccination to define lack of confidence in 201 vaccines, while our survey had a broader approach (i.e., it assessed confidence, safety, and efficiency) which can 202 thus include more people in this category.

203

Regarding the parents' sources of information on vaccination, it was clearly the doctor who gained the trust of parents with nearly 90% of them having sought information from their physician. This point is reassuring because it shows that parents trusted their doctor (General Practitioner or Paediatrician) and discussed vaccination with them. They also often obtained information from official sources (e.g., the vaccination schedule or official websites). Use of these sources of reliable information is encouraging. What is a concern, however, is the proportion of parents relying on information from relatives.

A US study from 2017 (7) found that parents reluctant or opposed to vaccination categories more often had a relative with a child that had experienced a severe reaction to a vaccine or whose parents were reluctant or opposed to vaccination. A large proportion of these same parents admitted to choosing a doctor who authorizes them to delay or refuse certain vaccines.

Here we could measure the influence of the relational environment of the parents: individuals who associate with people who distrust vaccines are more likely to similarly question vaccination (e.g., the benefits, risks, ...). This phenomenon is also very noticeable on social networks, where a "bubble effect" plays a major role in the increase in vaccine distrust (8).

218 Nearly 15% of the respondents stated they obtained much of their information from these sources, which are

often a long way from being objective and reliable. These people are therefore at risk of consulting sites that

220 display erroneous or anxiety-provoking information about certain vaccines and immunization in general.

221 It should be noted that just over 7% of the parents never sought information on vaccination. These people often

trust their doctor and they tend to diligently follow the vaccination recommendations for their children.

223

By comparing the fears raised by the parents to those found in the literature, we found that there was a lack of information on the subject or the feeling of information not being disclosed in some studies, as also noted in a 2017 US study that surveyed parents for HPV vaccination (9). This study also highlighted the pharmacist's potential role in increasing adolescent immunization coverage in Alabama, a region suffering from significant medical desertification, where pharmacists are authorized to vaccinate adolescents against papillomavirus.

Another interesting study, carried out in 2014 (10), made it possible to look for the main causes of international vaccine hesitancy. The same concerns were encountered as in our survey: fear of a disproportionate risk/benefit ratio (with a significant fear of side effects); problems relating to knowledge of and information on vaccination; but also, ideological, cultural, or religious issues (which we did not find in our study).

In regard to the parents' level of confidence in the various vaccines, the public no longer harbours doubts regarding the safety and the benefits of the oldest vaccines. Newer vaccines such as those for meningitis or hepatitis B are more controversial. In France, the latter is particularly controversial because of its purported link with an increase in cases of multiple sclerosis in a study dating back to 1998 (11), despite the fact that this has
since been disproven by many studies presented in the report by the Haut Conseil de la Santé Publique (HCSP)
(12). There is a high level of suspicion regarding the papillomavirus vaccine, with the lowest level of confidence
among parents in our survey. Its vaccination coverage is also the lowest of all of the vaccines used in France, with
only 18% of girls aged 16 receiving a dose in 2014 according to Public Health France (4).

241 Regarding vaccination rates against different diseases, it is clear that the lower the level of confidence, the lower 242 the vaccination coverage. We observed a correlation between these two parameters, which further proves that 243 mistrust of certain vaccines has a direct impact on immunization coverage and thus their preventive efficacy 244 against these diseases. Regarding the prevention of cervical cancer in young girls, we decided to weight the 245 results by focusing only on families that had at least one girl. This question was probably misunderstood by some 246 parents who responded when they did not have any girls in the family. We only considered girls aged 11 years and 247 over to determine the vaccination coverage of this group, the only one concerned by the vaccination 248 recommendation.

Here we measured the importance of rebuilding people's trust in these vaccines to increase individual and collective protection against these diseases that are still responsible for many medical complications resulting in hospitalization, disability, or even death.

252

253 Parents are actively seeking more objectivity about the sources of information: avoiding the positive or negative is 254 paramount. The benefits and potential risks of vaccines need to be addressed clearly so that parents can regain 255 confidence and make informed choices. Official communications from institutions are fundamental and need to 256 be prepared and argued for. The lack of coherence or transparency sometimes displayed by governments may have been one of the reasons for the reluctance to be vaccinated. Faced with authorities whose opinions may 257 258 sometimes seem too clear-cut and lacking in nuance, discussions that consider the benefits but also the risks of 259 vaccination would seem more acceptable. To be more persuasive, official communications should use scientific 260 information that is already available or can be quickly obtained. Strong scientific information already existed to 261 counter the claims of the anti-vaccine lobbyists for several of the vaccine-related scare stories that have emerged 262 in recent years, but the information was not used effectively at the outset. Authorities should study all available 263 literature without prejudice, in order to demystify vaccines and how they work - an important step towards 264 building trust and gaining the confidence of opinion leaders.

As health professionals, we need to provide an objective perspective on this subject: clearly pointing out the individual and collective benefits of the vaccines while explaining the possible undesirable effects and their frequency is a top priority. We also need to be open to discussing topics of considerable concern to parents, such as the use of aluminium adjuvants or the occurrence of rare diseases such as multiple sclerosis, macrophage myofascitis, or Guillain-Barré syndrome. There have been many studies on the subject to date and full transparency can often dispel doubts and fears of parents, thereby making them more confident about vaccination. These views should be adopted by all health professionals to increase immunization coverage.

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In the part "You and your pharmacist", the average level of trust the parents had for their pharmacist's vaccination advice was 6.84/10. The respondents pointed out in the free-expression section a considerable variability in the quality of the advice depending on the person who took care of them at the pharmacy. This result showed that people generally have confidence in their pharmacist, but that there is nonetheless ample room for improvement in our professional practice.

Concerning the potential new pharmacist engagements regarding vaccination, the proposal for a pharmaceutical
interview about vaccination was fairly well received by the parents with 52% of the responses in favour. A
pharmaceutical interview project regarding vaccination could be a solution to provide more information.

The notion that the pharmacist can remind patients of the date of upcoming immunization appointments was well received (54%). Indeed, thanks to modern dispensary software, all of this information can now readily be recorded in a secure manner. Clearly, a degree of remuneration for these pharmaceutical interviews or reminder for vaccination appointments would be useful to increase participation in these professional activities, as has been the case for anti-coagulants and asthma treatments.

We also asked parents how they felt about pharmacists being able to vaccinate under special circumstances. The results indicated a high level of opposition to this, with 58% of negative replies ("Do not agree at all" + "Mostly disagree"). The parents mostly saw this procedure as being something that should mainly only be carried out by doctors or paediatricians. On the other hand, others parents welcomed this initiative as time-saving and reducing the backlog common to medical practices.

In an IFOP survey conducted in 2016 (13), 92% of French people trusted their pharmacist and 65% of them thought that progression of the pharmacist profession towards providing more services and advice would be a step forward. In the same study, 66% of French people were in favour of the idea that pharmacists would be allowed to vaccinate against influenza (13% being fully opposed). These results are higher than in our survey where 42% of the parents were in favour of vaccination by the pharmacist. According to IFOP, the French people most in favour of vaccination at the pharmacy are seniors with nearly 68% having a favourable opinion. Those under 35 were more resistant to this idea, with 58% expressing a favourable opinion. Our results can be compared with this figure because it is likely that a number of our respondents, parents of children with a majority under the age of 11, belong to this group.

Regarding vaccination by pharmacists, the question is probably subject to a significant bias as in France it only concerns annual influenza prevention in adults with specific indications (14). This trial, which came into effect in the winter of 2017-2018 in some pilot regions, and will be generalized to the whole country from winter 2019, does not provide for any authorization to vaccinate the paediatric population. The way the question was framed in our survey, the parents may well have thought that it included the vaccination of children by pharmacists, which introduces a bias in favour of rejection of this measure.

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#### 308 Conclusion

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This study provides insightful information on parents' views and attitude in regard to vaccination. While many parents were not sure about vaccination, there was, in fact, little genuine opposition to vaccination. They often suffered from a lack of objective information. Many were looking for reliable data on the risks of vaccines and particularly regarding their effectiveness, their safety (e.g., disease risks or disability), their composition (e.g., questions regarding aluminium adjuvants in particular), and their tolerance (e.g., side effects and immune reactions). There is obviously a need for a strong collaboration between all health professionals to provide information, listening and reliable advice, as this is essential for promoting public health.

317

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	Do not agree at	Mostly disagree	Mostly agree	Fully agree	No answei
	all				
"I would	d like to be able to me	et with my pharmad	ist in a confidentia	l setting suitable f	or discussing
		vaccination if I	feel the need."		
	18.75%	27.08%	51.04%	1.04%	2.08%
	"Regarding the bill	that would allow pl	narmacists to vacci	nate patients, I an	n:"
	26.04%	32.29%	32.29%	6.25%	3.13%
·,	"I would like my pharm	nacist to remind me	of upcoming immu	nization appointm	ients"
	10 750/	25.00%	40 629/	10 E/10/	2 090/

- 363 Figure 1: The parents' sources of information regarding immunization
- 364 Figure 2: The parents' level of confidence in regard to the major vaccines (out of 10)
- 365 Figure 3: Declarative data of vaccination coverage in our sample
- 366 Figure 4: Parents fears about vaccination



Figure 1: The parents' sources of information regarding immunization



Figure 2: The parents' level of confidence in regard to the major vaccines (out of 10)



Figure 3: Declarative data of vaccination coverage in our sample



Figure 4: Parents fears about vaccination