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Effective Communication
in Outbreak Management for Europe

Under-vaccinated Groups in Europe: Who are they and how to communicate with them in outbreak situations?

Work Package 6 - EU project Effective communication in Outbreak management
Development of an evidence-based tool for Europe

E-com@EU is coordinated by Prof. dr. Jan Hendrik Richardus, Erasmus University Rotterdam. This EU project is directed at development of an evidence-based behavioural and communication package to respond to major epidemic outbreaks.

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Abbreviations

AEFI	Adverse Events Following Immunisation
CDC	Centre for Disease Control and Prevention (US)
CHC	Child Health Clinic
CBI tactics	Communication and Behavioural Influence tactics
CRIA	Centre for Research In Anthropology (Portugal)
DPOM	Determinants and Performance Objectives Matrix
DPT-IPV	Diphtheria-Pertussis-Tetanus-Polio vaccine
ECDC	European Centre for Disease Prevention and Control
HCW	HealthCare Worker
IM	Intervention Mapping
IPH	Institute of Public Health
MMR	Measles-Mumps-Rubella vaccine
MoH	Ministry Of health
NIP	National Immunisation Programme
NVKP	Nederlandse Vereniging Kritisch Prikken (The Dutch Association for Conscientious Vaccination)
OPD	Orthodox Protestant Denomination
RIVM	National Institute for Public Health and the Environment (The Netherlands)
SGP	Staatkundig Gereformeerde Partij (the Orthodox Protestant political party in the Netherlands)
UVG	Under-Vaccinated Group
VE	Vaccine Effectiveness
VPD	Vaccine Preventable Disease
WHO	The World Health Organization
WP	Work Package (Of E-com@EU)

Foreword

This report is intended to be a tool for health professionals, health agencies and Institutes of Public Health (IPH) throughout Europe to assist them in developing outbreak communication plans for Under-Vaccinated Groups (UVGs) (Definition given in 1.3.). We want to emphasize that this report is only one of many advocating specific communication tactics for increase uptake of vaccines. Examples of important guidance reports are the report on Behavioural Analysis, from Communication to Behavioural Influence, an Overview of Approaches and Issues as part of E-Com@EU Programme Work Package 3 (see Part II of this report) and the communication action vaccination guide for healthcare providers, Let's talk about protection: Enhancing childhood vaccination uptake by ECDC and World Health Communication Associates Ltd (WHCA) (see Appendix 14.4 (part II)).

Part I of the report provides an overview of UVGs in three selected European countries (Romania, The Netherlands and Portugal) and the determinants that influence these groups' decision(s) to, totally or partially, decline vaccination. In the original project plan considerable attention was envisaged for analyses of the influence of UVGs on the Internet and classical media. However, due to administrative and institutional limitations these analyses were cancelled.

In Part II, we describe and suggest possible CBI tactics for the most common determinants of declining vaccination and amenable to change. Some of these determinants are common between different UVGs, and also common to other individuals / groups in the general population in various countries - and were identified previously for routine vaccination and during the 2009 Influenza A(H1N1) pandemic. Therefore, we suggest that similar tactics could also be used for communication with the general population. In addition, they might also be beneficial in between outbreaks. This report thus touches also on topics that are relevant for other WPs of the E-com@EU-project.

Executive Summary

Scientific knowledge and technical possibilities have increased tremendously in the past years and have enabled health authorities to respond more effectively to major outbreaks. However, the ability of governments and health authorities to communicate the need for large-scale preventive measures such as vaccination effectively during outbreaks, and to increase the acceptance of vaccination among under-vaccinated risk groups has not developed to the same extent. Consequently, unvaccinated pockets remain in many European countries, which still experience outbreaks of VPDs with the danger of spreading infection to the general population and other countries.

This project aimed to suggest CBI tactics for Under-Vaccinated Groups (UVGs) for health professionals and agencies throughout Europe in case of major epidemic outbreaks of a vaccine preventable disease (VPD).

The first part of this report seeks to identify UVGs and to describe their determinants regarding vaccination in three European countries (Portugal, Romania and the Netherlands). From literature reviews, grey literature and on-going researches, we identified six UVGs:

- Anthroposophists;
- the Orthodox Protestant Denominations (OPD);
- The Dutch Association for Conscientious Vaccination (NVKP);
- Roma community;
- the 'macrobiotics';
- the 'critical citizens'.

The main determinants regarding vaccination were:

- the perceived non-severity of traditional childhood diseases;
- fear of vaccine side effects;
- doubts about the effectiveness of the vaccine;
- religious objections;
- protective effect of natural lifestyle;
- low access to healthcare centres;
- low trust in the Public Health authorities.

Among each UVG identified, there is a variety of beliefs and objections to vaccination and not all members have the same beliefs (within-group heterogeneity). On the contrary, some of the UVGs shared similar beliefs (between-group homogeneity). Therefore, we decided to develop behavioural and communication influence (BCI) tactics on the determinants most easily influenced or amenable to change and shared by most UVGs, rather than build a separate strategy for each UVG.

From this first part of the project, we developed a 'Determinants and Performance Objectives Matrix' (DPOM) which combines performance objectives (i.e. get the vaccination) for each selected determinant (i.e. vaccine effectiveness (VE)) where programme objectives were defined (i.e. ensure UVGs are confident in having enough information on VE) in order to achieve these performance objectives.

The inherent hypothesis of this approach is that a determinant-based approach may be more effective and efficient than a segmented approach based on specific sub-groups of the population such as the

OPDs, Anthroposophist and Roma communities. The potential efficiency of the programme may be significant given that such an approach might also apply to the general population among which similar determinants may play a role. What is not being advocated is a total disregard for the specific needs of specific segments of the population that resist actively or passively immunisation uptake. Rather the determinants-based approach can be integrated in more specifically segmented and targeted approaches based on specific sub-group characteristics.

In the second part of the project, via the DPOM tool, we suggest a number of evidence-based CBI tactics for UVGs. Health professionals and agencies can use these tactics effectively throughout Europe, in the framework of countries own national immunisation programmes (NIP), in case of major epidemic outbreaks of a VPD. It must be emphasised that the communication approaches set out here are not presented as a total and complete set of interventions; rather they are illustrative of a set of communications components of a fuller programme. Moreover, when communication programmes are being developed and implemented locally (or nationally), the specificity and the tendency of each UVG needs to be taken into account in framing that strategy.

A general principle that has emerged from this work is that communication with UVGs has to start as soon as possible. To be effective, responsible organisations should not wait for the next outbreak to initiate communication. Rather than having a reactive approach, there is a need to undertake regular, proactive communication and dialogue with these groups to build relationships and trust.

1. Introduction

Scientific knowledge and technical possibilities have increased tremendously in the past years and enabled health authorities to respond more effectively to major outbreaks. However, the ability of governments and health authorities to communicate during outbreaks the need for large-scale preventive measures such as vaccination, and to increase the acceptance of vaccination among the general population and specific under-vaccinated risk groups has seemed to be deficient.

Historically, certain people and groups – both in the industrialised and developing world - have resisted the idea of vaccination [1-3]. There is a broad range of motives why groups are resistant or critical towards vaccination [4], from religious and ideological motives to philosophical or purely emotional motives. Some of these (resistant / critical) groups have a considerable voice in the media, both traditional and modern [5, 6], and thus, potentially can influence wider public opinion regarding vaccination [7].

As new vaccines are developed, and new pathogens emerge, there is also an appearance of new opponents and/or new arguments, both for and against vaccination. Under-Vaccinated Groups (UVGs), which fully or only partially decline vaccinations offered in National Immunisation Programmes (NIP), are susceptible to refuse any new vaccination which may be advised by governments in case of a major outbreak, such as a pandemic. In this, UVGs could be seen as ”sentinels” in terms of ideas: they could be the precursors and amplifiers for some ideas against vaccination, and then, spread these ideas among the general population. These groups could also be seen as “sentinels” for acquisition of infection (due to low vaccination coverage) and then subsequently spread the infection to the general population.

1.1 Designing communication strategies for under-vaccinated groups

While poor vaccine uptake in some UVGs (Anthroposophists and Orthodox Protestants in the Netherlands and Roma populations in Europe) has been noted for a long time, their reasons for not vaccinating have not been studied in detail. Even in the most recent vaccine preventable disease (VPD) pandemic -the 2009 Influenza A(H1N1) pandemic- no specific literature exists on UVGs. However, studies have shown that some of their determinants for non-acceptance of routine universal childhood vaccines were similar to the determinants of low vaccine uptake of Pandemic influenza A(H1N1) vaccine identified among the general population in various countries during the 2009 pandemic [8-11].

Knowing the characteristics of UVGs that are opposed to or critical towards vaccination and improving communication with them is particularly crucial during outbreak situations. In order to develop possible communication strategies with these UVGs in case of an outbreak – and communicate with them in a trustworthy manner to fulfil their (information) needs in order to make a well-considered decision to vaccinate - we need to know more about their background, characteristics and beliefs concerning vaccination. We hope that the suggested CBI tactics via this project will be useful for promoting routine vaccination as well as vaccination in outbreak situations.

1.2 Aim of this Work Package

The main aim of this Work Package (WP) was to identify and describe UVGs in Europe and then, develop evidence-based CBI tactics for UVGs, that can be used effectively by health professionals and agencies throughout Europe, in the framework of countries own NIP, and in case of major epidemic outbreaks of VPDs.

1.3 Case definition of an Under-Vaccinated Group (UVG)

We define an UVG as a group within the population with low vaccination coverage[1] because of:

- Resistance, opposition, withstanding or critical towards vaccination because of personal, ideological, philosophical, cultural or religious reasons

and/or

- Difficulty accessing healthcare services / vaccination

AND, that is organised as:

- a 'closed' community (with close physical contacts e.g. going to the same school, churches, living on the same halting site/encampment) characterised by the same ideological way of life
- or as an association that shares common (often negative) beliefs regarding vaccination

Exclusion Criteria:
We did not include immigrants, individuals with low educational level, people living together in closed settings (e.g. elderly person's home, hospitals, prisons etcetera) in our case definition for UVGs, because, although they may have lower vaccination coverage or be living in the same setting, they are not necessarily organised as a community and living with/sharing the same ideological way of life.

Considerable vaccine resistance may be found among Healthcare Workers (HCW). This creates a conflict / duality, as many would envisage that this group should advocate vaccination and – in terms of acceptance of vaccination – potentially serve as a role model for the general population. Vaccination acceptance of HCW is discussed in WP3 of this EU project (http://www.ecomeu.info).

1 To achieve herd immunity for measles and rubella, a very high vaccination coverage of >95% is necessary for both doses of the vaccine, so that the vast majority of people who do not respond to the first dose of vaccine will develop immunity (http://www.euro.who.int/__data/assets/pdf_file/0020/79022/E81567.pdf).

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Part I: Identification and description of under-vaccinated groups in three European countries and their beliefs regarding vaccination

2. Introduction and objectives

In the first part of this report, we aimed to identify UVGs in three European countries and thereafter, describe their beliefs and arguments concerning vaccination.

3. Methodology

3.1 Selection of the three countries

In order to identify UVGs and to describe them, it was decided to focus on three European countries as three different examples. Working at the Dutch National Institute for Public health and the Environment (RIVM), we chose the Netherlands (north-western Europe) as one of the three. In order to have a geographical representativeness of European countries, we further selected Portugal (south-western Europe) and Romania (central/south-eastern Europe).

3.2 First two steps of the Intervention Mapping approach

For a health promotion programme to be effective it should follow a systematic approach and utilise a coherent theoretical base. Different methods exist to build such a programme. One of these methods is Intervention Mapping (IM) [12, 13]. This method has previously been used to develop programmes to increase vaccination uptake among HCWs [14, 15]. IM offers an approach to structure the programme and to develop theory- and evidence-based programmes and describes six different steps from the identification of the problem to implementing/achieving a plan [13, 15], as outlined in the table below.

Steps in an Intervention Mapping approach	
1	Needs assessment (identification of the (health) problem)
2	Definition of proximal programme objectives
3	Theory-based methods, and practical strategies
4	Programme plan
5	Adoption and implementation of the plan
6	Evaluation

We followed the first two steps of the IM approach – the needs assessment and the definition of proximal programme objectives - in order to define and describe our target population, identifying determinants of poor vaccine uptake, and suggesting CBI tactics on how to communicate with our target population.

We decided to use the first two steps of the IM to give a basis and a structural approach to IPH who want to plan intervention programmes using these communications tactics. Further steps of the IM approach (adoption, implementation and evaluation) were not part of this study. We recommend to IPH, which want to plan intervention programmes using these tactics to follow all the six steps of the IM. Indeed, it will help IPH to develop the best possible intervention, to improve the quality of the planning process and to conduct activities to achieve programme transparency.

3.2.1 The needs assessment: identification and description of the UVGs, and of the determinants of poor vaccine uptake among those groups

We conducted two literature reviews, including peer-reviewed and grey literature (e.g. published and unpublished reports of outbreaks, national reports on vaccination coverage, country-specific information on NIP and schedules of vaccination and online resources). The first literature review aimed to identify UVGs in Europe - our target population – and a second literature review in order to find the determinants concerning vaccination (both for and against) among those UVGs. See Appendix 14.1 for full details on the search strategy used.

Background information in terms of vaccination coverage and NIP of the three selected countries – considered important as vaccination decision-making could depend on the vaccination schedule and could be different whether vaccinations are mandatory or free-of-charge - are described in Appendix 14.2.

From the overall description of the UVGs and their beliefs concerning vaccination, we drew up a list of determinants of vaccine refusal for each of the UVGs, assessing the relative importance of each determinant in the decision to refuse vaccination. The relative importance of the determinants was qualitatively assessed by three independent researchers. From this list, we selected the determinants that were shared by three or more UVGs. The results of the needs assessment are described in chapters 4, 5 & 6.

Suggested steps to identify UVGs in any country:

1. Systematic literature review: it could be performed to identify UVGs in the literature based on outbreaks or low vaccination coverage studies within community, group or minority.
2. Specific studies/reports: outbreaks reports, beliefs towards vaccination (focus groups or questionnaires), reported participation in the NIP (questionnaire) [15], vaccination coverage, seroprevalence (age-specific humoral antibodies) studies [16].
3. Online sources: in case of an outbreak, new websites are usually created and current websites against vaccination are usually updated. Therefore, looking for dedicated websites and/or monitoring social media with specific keywords could help to identify UVGs (new or old).

3.2.2 Definition of performance and programme objectives

In this second step of the IM model, we defined performance objectives for each selected determinant answering to the following questions: what exactly do we want to do, change or improve concerning vaccination among these UVGs in case of major outbreaks? In order to achieve these performance objectives, we defined programme objectives. The programme objective is the way to answer to these questions for each selected determinant: how do IPHs have to communicate, and what do IPHs have to communicate with UVGs in order to achieve each performance objective? The programme objectives will help to build the CBI tactics per determinant and performance objective.
Moreover, because some determinants are common between different UVGs and because not all members within a group necessarily share the same ideas, we decided to develop communication strategies by determinant rather than by UVG.
The identification of the determinants, the performances and the programme objectives are presented in chapter 7.

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4. Results: Identified under-vaccinated groups in the three selected European countries

We identified UVGs described in this report by means of outbreaks within their community, by vaccination coverage studies and by detailed review of peer-reviewed and grey literature.

4.1 Identified UVGs

In **the Netherlands**, three UVGs were identified: **the Orthodox Protestant Denominations (OPD), the Anthroposophists and The Nederlandse Vereniging Kritisch Prikken (NVKP - Dutch Association for Conscientious Vaccination)**. They were already known by the RIVM to be critical of or opposed to vaccination.

Several outbreaks occurred in the first two groups and were identified by epidemiological investigations [16-23]. The NVKP is well known in the Netherlands because they are active on the Internet. It is an association of active opponents or sceptical persons concerning vaccination. No other groups were identified from the literature review and other research.

In Romania, the **Roma community** was identified as the only group, which met the case definition. Many outbreaks, especially measles, occurred within this community in different European countries [23]. No other organised group was identified by the IPH of Romania, or by the literature search. While our initial focus was on the Roma community in Romania, we decided to extend the description of the Roma community in this report to Bulgaria, Czech Republic, Greece, Hungary, and Slovak Republic because research already done by our collaborators in Romania included these countries. However, we did not look into whether the Roma are the main UVG in countries other than Romania, because these countries were not the scope of this study.

In Portugal, the **Roma community** was also identified as a group with concerns about vaccination. The IPH did not identify other groups that exactly met our case definition. However, anthropologic research was on going about the meaning and the experiential basis for some contemporary forms of vaccine acceptability in Portugal. Ethnographic researchers in Portugal were conducting in-depth, open-ended interviews with a range of actors, selected using 'snow-ball' techniques. These researchers identified two other groups with concerns about vaccination: people following an alternative dietary system, called in this report "**macrobiotics group**", and "**critical citizens"**. The critical citizens who are critical vaccine acceptors or vaccine refusers are not organised as a group as defined in this report. However, they shared common ideas and are a "(non)group" which seems to be growing. Developing communication strategies on the determinants of vaccine refusal particular to these groups seemed very useful and interesting for IPHs, therefore we decided to include them as well.

4.2 UVGs in Europe

These six identified "groups" (i.e. Anthroposophists, OPDs, NVKP, Roma community, the 'macrobiotics' and the 'critical citizens') are described as examples of UVGs in this report. While they are present in the three selected countries (i.e., the Netherlands, Portugal and Romania), most of them are not specific to those three selected countries and can be found in many European countries.

- The Anthroposophists also live in many other countries all over the world (http://www.goetheanum.org/fileadmin/aag/BroschAAG_e.pdf). In Europe, Anthroposophist societies are present in Germany, Poland, Great Britain, Austria, Hungary, Portugal, Belgium, Romania, Ireland, Slovakia, Italy, Czech Republic, Spain, Sweden, Finland and France. The

Anthroposophical Society has its international centre at the Goetheanum in Dornach, Switzerland.

- Similar associations to the NVKP with parents and healthcare professionals with the same beliefs have emerged in other European countries: as an example Cryshame (www.cryshame.com) and Jabs (www.jabs.org.uk) in UK, www.artdevivresain.over-blog.com in France.
- OPDs are also present in Canada and USA, but not in other European countries. The non-vaccination issue with this particular group is a typical Dutch problem.
- The Roma community is present in all European countries but especially in the central and south-eastern Europe.
- People following a macrobiotic dietary lifestyle can be found in many countries [24].
- Individuals, called in this report 'critical citizens', who fully or partly decline vaccination, can be found in various European countries, other than Portugal.

In other European countries than those selected for this project, additional UVGs were identified in our first literature review: Orthodox Jewish and Irish Travellers (see manuscript "Under-vaccinated groups in Europe and factors regarding their acceptance of vaccination; two literature reviews, to be submitted).

4.3 The Orthodox Protestant Denominations (The Netherlands)

Summary:

- The OPDs base their arguments regarding being vaccinated or not on the Bible. Because the interpretation of the Bible differs according to their denomination, the vaccination coverage varies between the denominations.
- The main argument against vaccination is the necessity to rely on Divine Providence: God decides on health and disease, man cannot and should not interfere.
- - The complete spectrum of vaccine acceptance is found in the various OPDs, from fully compliant to total rejection. The decision regarding childhood vaccinations is not based on the severity of the disease. Nevertheless, a small minority may accept 'second chance vaccination' during an epidemic of a serious disease such as polio.

4.3.1 Background

Since the 19th century, various OPDs have separated from the Protestant Church in The Netherlands. In these OPDs, 'predestination[2]', 'election[3]' and personal religious experiences play an important role [25-27]. The five most significant OPDs numerically are:

- Restored Reformed Church
- Reformed Congregations
- Reformed Congregations in the Netherlands
- Old Reformed Congregations
- Christian reformed Churches

The number of members of these various OPDs is estimated to be around 250,000, i.e. 1.5% of the Dutch population [25, 26]. Historically, most OPDs live in an area stretching from the south-west to the north-east of the Netherlands, the so-called "Bible belt". For demographic statistical analyses this area

[2] Predestination: God has ordained all that will happen
[3] Election: God has predestinated some to salvation, and others to destruction.

is usually defined as municipalities with vote rates for the Staatkundig Gereformeerde Partij (SGP), the OPD's political party, above 5% [26, 28]. However, almost one quarter of the members of the OPDs live outside this area.
The OPDs also constitute a cultural minority. They live in a closed community within Dutch society with their own churches, political party (SGP) and schools [26]. There are about 125 Orthodox Protestant elementary schools and 7 Orthodox Protestant high schools in the Netherlands [29]. In daily life religion plays an important role. The OPDs have their own newspaper and their own internet forum. For religious reasons they object to television, but internet is used for educational purposes and mutual contact [25, 27].

4.3.2. Beliefs about vaccination

Orthodox Protestant opposition to vaccination dates back to the 19th century when Capadose, an Orthodox Protestant medical doctor, published his objections to smallpox vaccination [30], suggesting that health and disease are given by God, and man should not interfere with Divine Providence.
The OPDs vary in their interpretation of the Bible, and - depending on the interpretation - may find in the Bible support for arguments for or against vaccination. [25-27]. Four groups were identified:

- traditionally non-vaccinating parents ('Divine Providence', intervention of man is not allowed),
- deliberately non-vaccinating parents ('Trust in God", personal relationship with God),
- deliberately vaccinating parents (Vaccination is a 'gift from God'; fear for side effects, interpreted as a sign from God)
- traditionally vaccinating parents (didn't relate vaccination to religion).

This results in different vaccination coverage among the various denominations [25]. All OPDs state that members are free to decide to be vaccinated or not, having to account for their choice only to God [27] and that the final decision is the responsibility of parents [30].

The main argument for those who refuse vaccination is the necessity to rely on Divine Providence; if God sends an illness to somebody or an outbreak on earth, God has a reason to do it and men must not oppose God [31].
Apart from religious arguments, family tradition also plays a role in OPDs decision-making on vaccination. A subgroup of Orthodox Protestant parents do not make a deliberate decision on vaccination and just follow the tradition within their family, and especially within this minority, the tradition is frequently not to vaccinate [30].
Medical arguments, like the effectiveness or side–effects of vaccination, are less important to this group. Orthodox Protestant parents who accept vaccination use religious arguments to justify why vaccination is allowed [30]. In a study among unvaccinated Orthodox Protestant youngsters to assess their need for information about vaccination, only 21% were interested in medical information on vaccination. Some of them said that they have enough information from biology lessons at school. In contrast, 53% were interested in information on religious aspects pertaining to vaccination, and 60% in information on their peer groups' opinion of vaccination; their preferred source of information is the NPV (Dutch Patients' Association), which is an association on biblical foundations, representing members who accept vaccination as well as those who refuse [25].

- **How HCWs communicate**

HCWs' approach to addressing religious objections to vaccination is influenced by the characteristics of the child, the willingness of the parents and their own characteristics [32], including religious background. Recent research suggests that while all HCWs provide Orthodox Protestant parents with medical information, this medical information does not seem to influence the vaccination decision-making of these parents [32].

Some HCWs discussed the decision-making: they verified how the vaccination decision was made; other HCWs also briefly discussed religious arguments for and against vaccination. This discussion depends of what parents want to know and if they are willing to talk about it. It also depends of the religious background of the HCWs. Good communication skills, positive attitudes to and knowledge about religious objections to vaccination of the HCWs seemed to be important for parents [32].

- **Communication with religious leaders**

Orthodox Protestant religious leaders also have different opinions on vaccination, according to the denomination they belong to [33]. The decision-making of their congregation is highly correlated with their own opinions for or against vaccination. Especially in OPDs with intermediate vaccination coverage, religious leaders are sometimes asked for advice on vaccination. Then, they meet parents and discuss about the Bible, decision-making and psychological consequences of the decisions. They stimulate parents to deliberately decide about vaccination. These religious leaders would like the national universal vaccination programme to remain voluntary. They are not willing to promote vaccination on behalf of authorities but are willing to discuss -in case of an outbreak- specific control measures rather than vaccination. They perceive that they cannot change their ideas about vaccination without a loss of credibility and authority because these beliefs are based on their interpretation of the Bible. Therefore, dialogue and communication between health authorities and these religious leaders will not persuade them to promote vaccine uptake.

4.3.3 Vaccination coverage

In 2006-2008, overall vaccination coverage among the OPDs, as measured by two sub-studies (an Internet survey among orthodox Protestant youngsters and a nationwide study on the immunity of the Dutch population), was estimated to be at minimum 60% [25] with a variation within OPDs. The Protestant Church in The Netherlands and the Christian Reformed Churches had high vaccination coverage >85%. The Restored Reformed Church and the Reformed Congregations had intermediate vaccination coverage: between 50-75%. The Reformed Congregations in The Netherlands and the Old Reformed Congregations had low vaccination coverage: <25%. This pattern is in accordance with an ecological study on the influence of OPDs on municipal vaccination coverage [26].

In a nationwide seroepidemiological study, the seroprevalence of tetanus-antitoxin (TT) antibodies – that cannot be naturally acquired, but only by vaccination- was 94% (CI 94–95%) in the general population, compared to 36% (CI 17–57%) among a subgroup of OPD [34].

4.3.4 Community Outbreaks

In the Netherlands, poliomyelitis [22, 35-40], mumps [18, 19], measles [16, 23, 41] and rubella outbreaks [20, 21, 42] have all been reported within this community.

4.4 The Anthroposophists (The Netherlands)

Summary:
Anthroposophists or parents with an anthroposophical view/lifestyle or beliefs:

- Are not against vaccination in general
- Perceive childhood illness as useful and salutary for the development of the body and of the mind of children, and as an important experience for parents (ideologies and beliefs)
- Prefer case-by-case ascertainment of need and discussion of risks; the decision/choice to vaccinate is an individual one and not a public health concern
- Prefer to be flexible in accepting, refusing or postponing childhood vaccinations and choose which vaccines they want according to their personal choice

- Favour natural remedies and a healthy lifestyle (e.g. healthy nutrition) as protection against infectious diseases
- Need more scientific information about vaccines and, diseases, such as side effects and severity of the diseases from the RIVM, and to communicate more objectively
- Would like monovalent vaccines (e.g. single antigen vaccines for measles, mumps and rubella (MMR) rather than the triple antigen MMR vaccine) and greater flexibility in the NIP schedule (to vaccinate with monovalent vaccines and vaccinate at different ages (later than in the NIP)
- Consider (although in a minority) that government policy is influenced by the pharmaceutical industry (negative feelings toward government interventions/ mistrust)
- Believe that governments want to eradicate paediatric illness because these illnesses are unacceptable in current Western society and cost a lot of money and time; demand from regular healthcare centres more information and time as is provided in the Anthroposophical Child Welfare Centres

4.4.1 Background

Anthroposophy is a spiritual movement founded at the beginning of the 20th century by Rudolf Steiner (1861-1925), an Austrian philosopher, social reformer, architect and esotericist. This movement postulates "the existence of an objective, intellectually comprehensible spiritual world accessible to direct experience through inner development" [31]. Steiner divided the development of the human body into four stages [23, 43]. Firstly, there is the physical body common to the inorganic world, developing until seven years old. This is followed by an etheric body common to plants, animals and humans until the puberty. Then a conscious body appeared common to animals and humans and finally there is the ego body unique to humans.

This theory was applied to different settings such as education, medicine, architecture and agriculture. Anthroposophists have developed schools, health centres and several institutions to follow, share and spread their beliefs and concepts. In September 2011, there were 1003 Waldorf or Rudolf Steiner schools worldwide, with 92 in the Netherlands and 13 in Romania[4]. No school was reported in Portugal. In the Netherlands, the Anthroposophical physicians are organised into the Netherlands Association of Anthroposophical Physicians. They complete a regular medical university degree followed by a three-year specialisation in Anthroposophical medicine and subsequent work at Anthroposophical clinics and healthcare centres.

In the Netherlands, the Anthroposophical Society counts 4,300 members but the true number of followers may be higher based on the number of institutions and schools [31].

4.4.2 Beliefs about vaccination

- **Childhood illnesses are useful**

Rudolf Steiner was not an adversary of vaccination but he believed that a spiritual education and life could have the same protective effect on disease as vaccination. Steiner suggested that "Vaccination will not be harmful if, subsequent to vaccination, a person receives a spiritual education"[5]. Childhood diseases are perceived beneficial during the first two stages of the development of the body (physical

[4] www.waldorfschule.info
[5] http://www.anthromed.org

and etheric) but after puberty, they are not so helpful. For Anthroposophists, childhood illnesses are valued positively because they are part of the child's physical [8] as well as spiritual development [44, 45]. For them, the experience of illness is an essential step to develop, strengthen body and mind and adapt to the environment [46, 47]. Illnesses are viewed as a necessary instruments in dealing with karma and the incarnation of the child [48]. The discomfort of the disease not only benefits the development of children but also the development of parents: it is a formative experience for both [31].

Perceived susceptibility to the disease
Anthroposophical parents know that their child could get the disease if he/she is not vaccinated [49]. They are also aware that some severe diseases are less prevalent because of vaccination [45].

Perceived severity of the disease
Anthroposophical parents believe that not all VPDs are severe, e.g. measles or mumps [45, 50]. However, in a study among physicians who were working at an Anthroposophical Child Welfare Centre (CWC), physicians mentioned that parents who visited this CWC have fear that their child might experience the target diseases of the NIP [49].

Perceived severity of the side effects of the vaccination versus consequences of disease
Side effects of the vaccination or of the disease were not mentioned in a focus groups study among parents with an Anthroposophical view [45]. In other studies, some Anthroposophists believe that side effects of the vaccines might be severe and that vaccination might have a negative effect at the immune system of the child [46, 50]. Moreover, Anthroposophical physicians reported that parents who visited an Anthroposophical CWC have fear for side effects of the disease [49]. Parents also recognise the risks of complications of diseases [23]. However, because of the complications after getting the disease, they believe that children may experience a leap in their development after recovery [31]. After puberty, they believe that suffering from measles is no longer beneficial and that there is a higher risk for complications (without the resultant benefit for an adolescent's development). So, Anthroposophical parents are not opposed to MMR vaccinations post-puberty [23]. When children did not acquire the disease, parents will reconsider vaccination when they are older.

Perceived benefits of vaccination
Some vaccines are perceived as useful for protecting their children against perceived severe diseases such as diphtheria, tetanus, or polio [45]. In one study, parents mentioned, for example, that their children are used to play outside and associate this with a risk for tetanus.

Perceived vaccine efficacy
Some parents have doubts about the effectiveness of vaccines and of their components [45].

- **Childhood illness is not acceptable in current society**

The Anthroposophists criticise the current western society for too much emphasis on efficiency. They believe that nowadays, parents do not have enough time to take care of their sick children because of their job and choose therefore to vaccinate their child. Anthroposophists believe that, for the western society, infirmity and illnesses are a nuisance and that diseases cost money to the society and therefore should be eliminated [31].

- **Lack of freedom and personal choice / conscious decision**

Anthroposophical parents do not refuse all recommended vaccinations. They believe that parents have to make their own choice. They may accept, postpone or refuse vaccination. Their choice could vary

between different vaccines. Generally, they consider that the MMR vaccination is not useful, while they have fewer objections against other vaccines (e.g. diphtheria, tetanus and polio) [31, 45]. Anthroposophists would prefer single-antigen/ disease-specific vaccines rather than combination vaccines, so that they can choose between individual vaccines/ target individual diseases. In addition, they believe that using multi-component vaccines overloads the immune system. Parents who visited an Anthroposophical CWC would like more flexibility within the NIP [45, 49], and consider that the NIP is too strict and not adaptable. They do not feel free to choose because they have to pay if they want to adapt the vaccination schedule: postpone it or choose monovalent (single-antigen) vaccines. Parents feel responsible if their child has a negative outcome after getting the disease without being vaccinated, but they are prepared to accept that [45].

- **Social influence, perceived norms**

Parents with an Anthroposophical view indicate that they make their own choice about vaccination and are not influenced by their social environment, such as family or friends [45]. They mentioned that they experience sometimes negative reactions from their friends and families because they choose to refuse (some) vaccinations [45] for their children. Consequently, some parents refuse to talk about childhood vaccination within their social environment to avoid such reaction.

- **Healthcare centres: practical issues and communication**

Anthroposophical parents sometimes have negative experiences with regular CWC [45]: HCW usually tried to make them feel guilty if they refused or postponed vaccination and parents feel that there is insufficient time to discuss this issue. Parents who visit Anthroposophical CWCs are more critical and sceptical about vaccination than parents going to/visiting the regular CWC [49]. Contrary to the regular physicians, Anthroposophical physicians give more information about vaccines, they are more easily willing to adapt the vaccination schedule to the demands of the parent of the child if parents would prefer to have access to certain monovalent vaccines rather than combined vaccines (for example MMR). More time is dedicated for the parents at an anthroposophical CWC, and therefore, they can also ask more questions. Anthroposophical physicians reported that parents also would like to have more scientific information about new vaccines and about the severity of the VPDs [49].

- **Lifestyle**

Anthroposophists believe that with a healthy life and good nutrition (e.g. breastfeeding for babies), the immune system of children might be stronger and better able to fight against infectious diseases [45]. The parents also mention that - what they call a ‘safe environment’ e.g. mothers who stay at home to take care of their children - is also good for their children and may prevent them to get an infectious disease [11].

- **Critical about government, Public Health Institute and pharmaceutical companies**

Anthroposophical physicians and parents are quite sceptical about the role of pharmaceutical industry and governments, and believe there is a conflict of interest. In fact, some think that the pharmaceutical industry has a strong influence on the NIP policy [49]. Besides that, they believe that the IPH tries to evoke fear in people to convince them to vaccinate their child, but that these fear-based tactics are not useful, not objective and not convincing at all [45, 49].

- **Information need**

While parents with Anthroposophical beliefs do not trust the information provided by the IPH, they also think that the IPH is the most reliable organisation to give information about the NIP. They would like to get more scientific information about risks of vaccination and components of vaccines from the IPH.

Scientific articles about Anthroposophical medicine or lifestyle are available in peer-reviewed journals, with Anthroposophical medical doctors and researchers evaluating Anthroposophical clinical practices [51-53]. For example, some studies were done to show a link between measles infection and allergic disease among children. It was shown that measles infection [54] or Anthroposophical lifestyle [55-58] could reduce the risk of allergy or atopic syndrome among children.

4.4.3 Vaccination coverage

Parents who adhere to an Anthroposophical lifestyle participate less in NIP in the Netherlands than those with no Anthroposophical lifestyle [49]; similar results have been found in Germany [59].

A 2003 study conducted among 57,382 children from 5 to 12 year olds in Amsterdam showed a vaccination coverage of 93.0% for Diphtheria-Pertussis-Tetanus vaccine (DPT-IV) and of 93.9% for Measles-Mumps-Rubella vaccine (MMR) [60]. Among the 353 children in the study who attended an Anthroposophical school, 79.6% were fully vaccinated for DPT-IV and 65.4% for MMR, 14.7% partially vaccinated for DPT-IV and 6.5% for MMR and 5.7% completely unvaccinated for DPT-IV and 28% for MMR.

In addition, during the 2009 Influenza A(H1N1) pandemic, a study was conducted among parents who accepted pandemic flu vaccine for their child (n=1227) and parents who refused it (n=1900) [11]. Among parents who refused vaccination for their child, 10% mentioned principal convictions (religious) or beliefs in alternative medicine as Anthroposophy or homeopathy.

4.4.4 Outbreaks in their community

Measles outbreaks among Anthroposophical communities have been reported in the United Kingdom [61], Austria [62, 63], and Germany [50], and measles and mumps outbreaks in the Netherlands [17, 18].

4.5 The Dutch Association for critical vaccination (NVKP) (The Netherlands)

Summary:
Parents who adhere to the NVKP are heterogeneous, and present diverse beliefs:

- Do not absolutely reject all childhood vaccination
- Some experienced adverse events following immunisation (AEFI) in their proximity
- Emphasise damages of vaccination: vaccination could be harmful, side effects could be severe. Some of them still think that there is a link between MMR vaccination and autism.
- Have doubts about the necessity of some vaccinations because they believe that some diseases are not severe, can be easily cured and that the protection of vaccination is limited
- Prefer a natural lifestyle (some), like Anthroposophists or Homeopaths, and prefer natural medicine
- Think that the links between AEFI and vaccination are not sufficiently investigated and AEFIs are not registered (limited availability of information)
- Would like large-scale clinical trials of vaccines, and laws to address registrations of potential vaccine-associated adverse events
- Consider that there is a conflict of interest between government, RIVM and the pharmaceutical industry (some), and economic considerations. Therefore, they do not trust these institutions

4.5.1 Background

The NVKP (www.nvkp.nl) is an association founded in 1994 by a group of people who experienced negative consequences of vaccination (either in their professional capacity or from their own experience as parents) [4, 31], with a voluntary membership of around 1600 members. These members have heterogeneous backgrounds: concerned parents, persons with critical attitudes toward government, adherents of homeopathy, Anthroposophy or natural medicine [31]. Some members are family doctors/general practitioners[6]. One of the co-founders was a nurse who experienced negative reactions to vaccination and who felt unable to effectively answer many parents concerns about vaccination [4]. The association has a variety of objectives concerning vaccination: to provide information about vaccine-preventable diseases, vaccines, the impact of vaccination, treatment options after vaccination damages, and alternatives to vaccination (like homeopathy or treatments which they perceive as natural). They give a lot of documents and information on their website. The NVKP provides online guidance and organises congresses. They support parents who had problems with vaccination, and those who do not want to vaccinate (partially of fully) their children.

They are independent of any ideology or philosophy and the association is open to anyone with questions and problems regarding vaccination. Actually, they do not absolutely reject vaccination but they try to weigh up arguments for and against vaccination and they clearly support the free and individual choice to be vaccinated and against each illness.
To emphasize their beliefs and arguments they use part of the selected scientific literature apart from that produced by the pharmaceutical industry[7]. They maintain close contact with various similar foreign associations. Their arguments are also based on various international anti-vaccination websites [64].

People adhering to the NVKP are living scattered in the country, do not have close physical contact, therefore outbreaks will likely not occur. However, their activity on the Internet might influence people's attitude and intention to vaccinate.

4.5.2 Beliefs about vaccination

They have a variety of objections but they are not shared by all members [31].

- **Perceived severity of the disease and benefits of vaccination**

Firstly, some members wonder about the necessity of vaccination. They think that some VPDs are not severe and that they can be easily cured. In addition, they question the protection of vaccination.

- **Lifestyle**

Secondly, some of them are more in favour of natural methods of treatment such as homeopathy or natural medicine, and/or they have an Anthroposophical lifestyle. Homeopaths stress the damaging effects of vaccination: they explain that there is a wide range of symptoms after vaccination, called 'Post-vaccination syndrome' which can be avoided by not vaccinating. They prefer natural treatments, which "naturally promote and enhance the body's self-healing capabilities". Natural medicine is, for example, eating well, drinking clean water, teaching and learning safe behaviours. Those with an Anthroposophical view think that illness is essential for the child's development.

[6] Unpublished Master thesis Radboud University - Lopke Spaarman
[7] Unpublished Master thesis Radboud University - Lopke Spaarman

- **Vaccination is harmful**

Thirdly, the NVKP strongly emphasises the potential harm of vaccination. They believe that the risks of AEFI are not well known, especially when a new vaccine is introduced. Furthermore, they believe that the effectiveness of vaccines and the registered AEFIs are not sufficiently investigated. The NVKP demands large-scale clinical trials to test vaccines, a registration of the side effects and a policy about vaccination damage. They still believe that there is a link between MMR vaccination and autism. Safety of components of vaccines is also questioned.

- **Do not trust government, Public Health Institute and pharmaceutical companies**

The NVKP believes that there is a conflict of interest between government, the IPH and pharmaceutical industry. They think that money plays an important role in influencing public health decision making regarding vaccines, and that vaccination takes place for economic reasons. For them, the IPH withholds information (about side effects for example), does not implement enough research and does not recognise potential and actual damage and ill health caused by vaccination.

- **Lack of freedom and personal choice**

Finally, they argue that parents should make their own choices concerning vaccination, but they have the feeling that they are not really free to make those decisions, due to strong social and medical pressure. Indeed, they think that parents who decide to refuse vaccination are put in bad light by their environment (friends, colleagues) and by the Public Health Authorities.

4.5.3 Vaccination coverage

No information is available on vaccination coverage among NVKP members.

4.5.4 Outbreaks

No information is available.

4.6 Roma population (central/eastern/south-eastern Europe and Portugal)

Research on the Roma community in central/eastern/south-eastern Europe was carried out as part of a project funded by the European Centre for Disease Prevention and Control (ECDC) and implemented by Romani CRISS[8], and is extracted from a research report issued by ECDC (not yet published).

Research on the Roma community in Portugal emanates from research projects coordinated by Manuela Cunha and Jean-Yves Durand: "Vaccination, society and the body. Anthropological approaches", FCT: PTDC/ANT/1637/2006 (Foundation for Science and Technology) and "Vaccination and Care, power and uncertainty", Centre for Research in Anthropology (CRIA). The materials used in this section are published in [65, 66].

Summary:
Among the Roma community in central/eastern/south-eastern Europe:

- No cultural or ideological reasons for opposing childhood immunisation
- Gap in vaccination coverage between Roma and the general population in most European countries with a large Roma population
- Failure to vaccinate is often unrelated to attitude towards vaccination; many vaccine rejecters let their children be vaccinated for fear of sanctions or because of liaisons' (health mediators/health visitors) work, whereas many Roma parents who wish to vaccinate their children fail to do so because of low access to healthcare

[8] Romani CRISS (Centrul Romilor pentru Intervenţie Socială şi Studii) – the Romani Center for Social Intervention and Studies, a Romanian non-governmental organisation (NGO)

- Main determinants for failure to vaccinate are poverty, low level of education, and mobility (between and within country)
- Considerable variation in knowledge level about vaccination
- Information acquired from authority sources (doctors, nurses, health mediators) and experience suggests the community tends to be largely favourable to vaccination. Rumours and media reports often challenge the positive representation of vaccination and lead to a polarization of opinions among the Roma communities.
- Among the Roma community in Portugal:
- More recent studies have shown higher levels of vaccine acceptance
- In the recent past: views about a “Gypsy way of life” (outdoor lifestyle and greater exposure to the elements) that provides a natural immunity, promotes bodily resilience in children and thus renders vaccines unnecessary.
- - Currently: views about vaccination as contributing to “matrimonial capital”, social integration and social reproduction of the community by preventing children from getting compromising diseases.

4.6.1 Background

Estimations indicate a total Roma population in Europe in the range of 8-12 million people [67]. Although Roma are territorially dispersed, almost half of European Roma are found in three countries – Turkey, Romania, and Russia. Other countries with estimated Roma populations over 500,000 persons include Bulgaria, Spain, Hungary, and Serbia.
A recent survey carried out by the European Agency for Fundamental Rights about Roma living in compact communities in 11 European Union countries found out that Roma represent a vulnerable population, whose members fare worse than the general population in terms of employment, education, income, and exposure to discrimination [68]. These structural inequalities also affect the health and access to healthcare services of the Roma community. The findings of a survey conducted in 2009 indicated that 15% of Roma have disabilities or chronic illnesses; 28% of Roma minors are not fully immunised; and one third of Roma have never seen a dentist [69].

4.6.2 Vaccination – attitudes and behaviour

In central/eastern/south-eastern Europe:

- **Diversity of attitudes**

The Roma ethnic group is culturally heterogeneous and its members occupy various positions in the social structure. It comes as no surprise to encounter a similar stratification in the attitudes towards childhood immunisation.
Research conducted in the six European Union countries (Romania, Bulgaria, Czech Republic, Greece, Hungary, and Slovak Republic) with the highest Roma populations revealed four types of attitudes towards vaccination: (1) enthusiastic support; (2) ignorance, nascent passive acceptance; (3) concerned passive acceptance; and (4) rejection:

1. ***Enthusiastic support*** refers to awareness of the purpose of vaccination, agreement with it, and a generally proactive behaviour. Well-informed parents who trusted their family doctor and had positive personal experiences with vaccination were most likely to exhibit this attitude. Some of the parents in this category were not only willing to immunise children according to the national vaccination schedule, but also expressed interest in vaccines not offered routinely in all public health programmes.

2. ***Nascent passive acceptance*** refers to absence of opposition to vaccination accompanied by weak intrinsic motivation to immunise children, having limited knowledge on the issue. Parents displaying this attitude tend to consider that the endorsement of the vaccines by the state or by the family doctor suffices to justify its utility. However, vaccinating appears to be a careless activity, most ignorant parents having limited and very general expectations from vaccines.

3. ***Concerned passive acceptance*** refers to absence of opposition to vaccination accompanied by weak intrinsic motivation to immunise children, having doubts regarding efficacy, and worries about vaccine administration and side effects. Concerned accepters tended to accept that vaccines are useful in many cases, but also pinpointed some perceived risks – developing the disease against which one is vaccinated (either because of or in spite of vaccination); exposing children to be vaccinated to interaction with sick children in the doctor's office; and getting (generally mild) side effects.

4. ***Rejection*** refers to refusal to immunise based on beliefs that vaccines are detrimental to the health of the child. The discourse of rejecters concurred with that of passive accepters in terms of presenting possible risks. However, rejecters tended to consider that risks considerably outweigh benefits, vaccines potentially exposing children to temporary or permanent disability or even death.

It should be noted here that the categories mentioned here emerged from the empirical data collected as part of the project, and should be regarded as ideal-types. In practice, there is a great deal of variation within each of the categories. Moreover, "nascent passive acceptance" was sometimes employed as a rhetorical strategy by some respondents who, albeit properly informed about the issue, refused to take a clear position on the grounds that they were not qualified to comment on public health policies. In other words, it was a matter of caution, modesty, and polite avoidance of taking a position, rather than an actual expression of the personal attitude towards vaccination.

- **Favourable attitudes are dominant**

Both family doctors and Roma parents belief that Roma have favourable attitudes towards vaccination. There were few rejecters and they were not localised in the same communities. Also, most participants indicated that failure to vaccinate is not a widespread problem in their locality.
From the accounts of the Roma respondents, it appears that immunisation is normative; people failing to have their children vaccinated are symbolically sanctioned, being represented as migrants, marginal, and outsiders.

- **Lack of ideological opposition to vaccination**

The study recorded extremely few cases of Roma parents refusing to vaccinate children because this would contravene to personal beliefs; most of them were Jehovah's Witnesses. At the same time, not all Roma members of the Jehovah's Witnesses rejected vaccination. Apart from religious reasons, the study did not document other ideological reasons to oppose childhood immunisation among Roma.

- **Disconnect between attitudes and behaviour with respect to vaccination**

Decisions pertaining to immunisation behaviour are not grounded solely on personal beliefs about the benefits and risks of administering vaccines. Many rejecters accept to have their children vaccinated either because of the work done by liaison personnel, such as health mediators and health visitors, or for fear of negative sanctions. These include being refused access to educational institutions (in

Bulgaria, Greece, and Hungary), fines (in Czech Republic and Slovakia); discontinuation of children's allowances (in Bulgaria) and 'trouble' with social work services.
At the same time, not all Roma favourable to vaccination have their children vaccinated, with some failing to do so due to structural issues, such as poor access to health services.

- **Determinants of low vaccine uptake**

One important finding of the study is that Roma who refuse vaccination tend to represent a minority among Roma communities. However, given the qualitative nature of the research, quantitative research is needed to validate this finding.
Poverty, low level of education, and temporary migration have been identified as determinants of non-compliance with vaccination requirements among Roma. In the European Union, mandatory vaccines and most recommended vaccines are provided free of charge and there is no cost for administering the shot. However, the indirect costs associated with vaccination (e.g. transport) represent a burden for many Roma families in need. Particularly exposed are families living far from the doctor's office, enrolled with a practitioner in a different locality than the one before, or having many children. Poorly educated parents tend to have more difficulties in understanding the rationale for vaccination. They are also more likely to stop an already commenced vaccine schedule after exposure to information about potential vaccine side effects. Particularly vulnerable are the illiterate, who represent up to 5% of the Roma population in Bulgaria; 10% in Romania; and 35% in Greece.

Roma in temporary migration (be it domestic or international) tend to experience difficulties in coping with the vaccination schedule as it is often difficult to enrol with a family doctor in the place of destination where different vaccination schedules may exist and where other arrangements may be necessary to access vaccination (e.g., requiring health insurance).

- **Knowledge of vaccination and sources of information**

The study revealed considerable variation in the amount of knowledge pertaining to vaccination among Roma. Interviews with doctors indicated that many Roma are unaware of the reasons for vaccination programmes and do not have adequate knowledge on the potential side effects of vaccines. Moreover, communication with Roma was often considered by doctors to be difficult, time-consuming, and frequently inefficient. The differences in class/hierarchy and cultural background as well as doctors' lack of training in intercultural communication may explain to a large extent the failures by healthcare professionals to properly informing Roma parents about vaccination. In these conditions, although medical staff represent the most legitimate sources of information, many Roma rely more on direct, personal experience and the experience of people in proximity in the community (e.g. family and friends) to form an opinion on vaccination.
Information acquired from authority sources and experience tends to be favourable to vaccination. Rumours and media reports often challenge the positive representation of vaccination and often lead to a polarization of opinions within the Roma communities.

Roma communities in Portugal:

- **Changes in vaccine acceptability**

Studies on the health situation of Roma communities in Portugal have reported the lack of preventive practices, especially the lack of routine vaccination of children [70-74]. However, more recent studies have shown higher levels of vaccine acceptance and uptake [75].

- **Notions about natural immunity tied to Roma activities and a "Gypsy way of life"**

In an ethnographic study following Roma communities in the region of Porto for almost two decades since the 1990s, Maria José Casanova [85] has shown changes in Roma attitudes towards vaccination. Non-regular vaccination in the 1990s was associated with prevailing cultural notions about natural immunity tied to the "Gypsy way of life". According to Roma understandings, the predominance of an outdoor lifestyle and the higher exposure to the elements would promote bodily resilience in children and render vaccines unnecessary.

- **Vaccination as contributing to "matrimonial capital", preserving social integration and the social reproduction of the community**

In recent years, attitudes towards vaccination showed more receptiveness. Notions about natural immunity gave way to an investment in health and the body, not only as a way to prevent risks and preserve physical well-being, but also to promote success and effective social integration through marriage within the group. According to cultural definitions, no Roma would want to marry an 'impaired person', affected by a preventable disease. In a restricted universe of potential partners, limited by ethnic endogamy, vaccines help prevent diseases, which would endanger one's children's future matrimonial capital in aesthetic and functional terms. Vaccines are thus part of a strategy not only of physical but also of social reproduction.

4.6.3 Vaccination coverage

Data on vaccine coverage among the Roma population are scarce and come primarily from surveys, given that most European countries do not collect statistics on minority sub-group within their medical systems. A study conducted in 2009 in seven EU countries found out that on average over one fourth of Roma children (28.4%) do not fully adhere to the national immunisation schedules in those countries, i.e. approximately 300,000 children [69]. According to the same source, vaccination coverage among the Roma population is lower than the average coverage among the general population in Romania (45.7% of Roma minors failed to adequately follow the child vaccination programme), Greece (35.3%), and Bulgaria (28.9%). In contrast, less than 10 per cent of Roma children did not properly adhere to the vaccination programme in Spain (9%), Portugal (5.3%) and Czech Republic (2.6%). One Portuguese national study [76] points to 96% of Roma children complying with the National Vaccination Plan.

4.6.4 Outbreaks in Roma community

In the past few years, several measles outbreaks have been described in areas with large Roma populations [23, 77-85].

4.7 Macrobiotics and critical citizens (Portugal)

This research follows up on the research projects coordinated by Manuela Cunha and Jean-Yves Durand: "Vaccination, society and the body. Anthropological approaches", FCT: PTDC/ANT/1637/2006 (Foundation for Science and Technology) and "Vaccination and Care, power and uncertainty", CRIA. The materials used in this section are published in [65, 66].

Summary:
For macrobiotics:

- A healthy food and lifestyle provide a strong immune system and protect against disease
- Childhood illnesses are seen as useful to build 'a resistant organism'; consequently vaccines are 'a damaging aggression' since they prevent the body from spontaneously creating its own natural defences
- Are suspicious of pharmaceutical industry and of global institutions' securitization policies

- Look for information on vaccination not in the process of making a vaccination decision but more to justify their decision of not vaccinating

For 'critical citizen' parents:

- Show a plural combination of health practices, types of consumption ("natural", "pharmacological") and therapeutic resources ("alternative" and biomedical).
- All have concerns about safety and risks of vaccination
- Pattern expressed by most of these questioning parents in relation to vaccines goes hand in hand with emergent forms of assertive citizenry, claiming more leeway for individual choice, participation, and negotiated decision-making – not only vis-à-vis vaccines but also other health matters and education
- Actively tap multiple sources of information, show health-awareness, self-reflection and an information-seeking attitude
- Do not relate passively with biomedical authority—or any authority
- Authoritarian frames of communication by healthcare professionals alienate, rather than promote, vaccine acceptance among them
- Decisions on vaccination are based on context-specific factors. Abstract moral judgements by others do not produce vaccination conformity but have instead counterproductive effects
- Otherwise, seemed more open to reconsider their views based on collective changing circumstances, or on advice given by the individual health professionals they consult

4.7.1 Alternative dietary systems: macrobiotics

The system of practices and perceptions about the body involved in macrobiotics leads to a type of questioning which promotes vaccine avoidance. However, resistance to vaccination is not extended to all of its practitioners. In Portugal, macrobiotic groups and their tendency to vaccine avoidance were studied by Virgínia Calado [86], in a qualitative study conducted between 2005 and 2010 in two Portuguese cities.

- **Health as a natural capacity of resilience based on diet and lifestyle**

Considering health as a process, and as the natural capacity to overcome disease, macrobiotics single out food and lifestyle as the most important aspects for having a strong immune system. In this perspective, this is evaluated in terms of a particular balance in blood chemistry. Diseases could be naturally prevented, as well as defeated, by means of a diet providing this chemical balance. A balanced organism and a strong immune system "repel" diseases, an unbalanced and weak body "attracts" them: "It is not the mosquitoes [i.e. viruses] that generate swamps, it is the swamps that generate mosquitoes" [86].

- **Childhood illnesses are beneficial, vaccines tamper with the creation of natural defences**

Nonetheless, some diseases, such as measles, would ultimately be beneficial by triggering "elimination processes" considered essential for building a resistant organism. From this point of view, biomedicine blocks these processes and vaccines are a damaging aggression since they prevent the body from spontaneously creating its own natural defences.

- **A coherent "alternativist" stance impervious/immune to biomedicine and pharmaceuticals**

This system of ideas aiming at a “natural” resilience (through diet and “elimination processes”) also often combines with an environment of suspicion towards biomedical knowledge and the profits of the pharmaceutical industry, thereby fostering general doubts and mistrust cast on the global institutions’ securitization policy.
These macrobiotic practitioners adopt an “alternativist” stance that tends to be highly coherent in terms of therapeutic views (mostly impervious to biomedicine and its experts) and types of consumption (circumscribed to the “natural” and excluding the “pharmacological”).

- **Information is less sought to previously inform a decision on particular vaccines than to retroactively justify anti-vaccination when confronted with criticism**

The adoption of an anti-vaccination stance tends to be part of an entire, direct, and identity adherence to an “alternative package” (a philosophy about health and disease, therapeutic views and practices, diet, lifestyle and types of consumption). The adherence to this “package” and to an anti-vaccination philosophy tends to take place within the macrobiotic social scene (through other practitioners, or lectures promoted by macrobiotic centres or taking place in macrobiotic shops and restaurants). The search for specific information on particular vaccines and vaccination tends to be instrumental afterwards, which is, not so much as a basis for building a decision, but more as a way to justify to others a decision that has already been taken on a more general philosophical set of beliefs.

4.7.2 Critical citizens (critical vaccine acceptors or vaccine refusers)

According to an ethnographic study conducted by M. Cunha and J.Y. Durand between 2007 and 2010 among parents and healthcare professionals in three Portuguese cities [65, 87], the pattern expressed by most parents who question vaccination is not aligned with a specific social scene, nor is it predicated on a pre-given particular philosophy such as macrobiotics. Although some features may coincide with the ones expressed by the adherents to this or other philosophy like Anthroposophy[9] (e.g. concerns about the perceived aggressiveness and allergenic effects of an excessively precocious, massive, and concentrated administration of vaccines in early age), they are not articulated in the same way.

- **Patterns: not alternativist, but pluralistic**

Health choices express a plural combination of health practices and an eclectic pattern in which different therapeutic resources coexist (e.g. homeopathy and biomedicine) [88]. Even though certain “pluralistic” health practices appear similar to some “alternative” ones when considered separately (vegetarianism, the consumption of healthy/organic food, the preference for the “natural” over the “chemical”), as a whole they differ in the degree of systematic and internal coherence. Lifestyles are heterogeneous and combinations of health practices and types of consumption do not tend to form a “package” in the same way. They are more open, varied, and unpredictable in the “pluralistic” variety: in one family, every member is vegetarian, vaccinated, and “follows conventional medicine, but in a critical way”; in another, children are not vaccinated, but dietary concerns are limited to the avoidance of “processed food, canned food and too much sugar. Otherwise, outside home we eat everything”.

Even though some “vaccinophobic” themes are shared, the safety and risks of each vaccine and the circumstances of vaccine administration to each child are weighed in more specific terms (e.g. following up on specific vaccine-science controversies).
Most of these “pluralistic” parents who were vaccine-decliners and partial vaccine-decliners held less polarised and more provisional views on vaccine issues than the “alternative” type. They seemed more

[9] Some of these parents mention a loose and partial adherence to anthroposophical ideas, which they combine with a variety of other views.

open to reconsider their views based on collective changing circumstances; in the same way they seemed more open to advice given by the individual health professionals they consult.

- **Processes: decision making and relationships with expert authority**

Instead of choosing an alternative authority over an instituted one (e.g. alternative therapies and experts vs. biomedical ones), these parents adopt an active questioning of any authority. They subject it to a personal scrutiny according to their specific situations, to the information they seek on their own, and they ponder the suitability of the different options at hand.
Decision-making is an on-going process, a process that is shaped through healthcare professionals, print media and internet-based knowledge [89]. Parents use the internet autonomously as a source of vaccine information and a forum for discussion. But the way it impacts on their choices is mediated by networks of friends, peers, and healthcare professionals. This autonomy is not self-sufficient, but relational. The self-management of information flows exposes parents to potential contradictory messages stemming from different sources. Parents thus recognise the importance of the doctors' role in helping them navigate this information.

They start to choose healthcare professionals, mainly doctors and paediatricians, as their first interlocutors and seek their advice in the first place.

- **Frames of communication with healthcare professionals**

Parents react negatively to a frame of communication with healthcare professionals based on "medical authority-patient passivity" [90-92]. In their health-awareness, self-reflection, and information-seeking disposition they do not relate passively to biomedical authority. They actively tap multiple sources of information and they derive their own evidence from their personal experience – for example, parents spontaneously mention the absence of allergies in their unvaccinated children compared to others in their own immediate environment.

In their relationship with healthcare professionals, they seek an opportunity to obtain and discuss information. These parents relate with the Portuguese "National Vaccination Plan" in the same way they relate with doctors, that is, as active, vocal interlocutors who do not delegate the power of decision over their bodies to higher authorities without critical scrutiny. They thus expect to be informed about the medical options adopted. They relate with vaccines and vaccination in the same way as they relate with medication. The acceptability of vaccines shares aspects with the kind of compliance they express regarding medication and prescribed drugs.

Some doctors adopted a collaborative role typical of shared decision-making vis-à-vis parents, that is, they tried to combine patient's active questioning with the promotion of decisions that refer to evidence-based and research-based knowledge. Most parents who reported this type of interaction ended up opting for vaccinating their children after a long process of reflection and hesitation about several vaccines, or even reversed previous decisions not to vaccinate.

Other healthcare practitioners were not willing or able to communicate[10] by contextualizing, mediating, and assisting parents in navigating the information they had, or to cope better with their questions and

[10] It is relevant to put these two different frames of communication in perspective. A national study on compliance [93] showed that well beyond a "gratitude bias", Portuguese doctors inspire in patients high levels of trust and satisfaction in terms of prescribed treatment and "technical" competence. However, satisfaction is much lower in other aspects, such as doctors' ability to take patients' opinion into account, to present them with therapeutic alternatives, and to make room for them to make questions and to express themselves. On the other hand most patients, contrary to the parents approached in Cunha and Durand's study, show low levels of autonomy and tend to adopt a passive attitude during consultations, abstaining from dialogue and leaving the initiative to doctors. This pattern of communication is thus co-constructed; it does not arise out

concerns. This leads to parents eventually looking for support on their own. They find it in the only channels left available to them: anti-vaccination leagues and anti-vaccination sites. Thus, what had started as a negotiated convergence with biomedical views and with the rationale of the National Plan of Vaccination ended up in a general alienation from these views.
In sum, parents end up declining vaccination because they actively question themselves about vaccines and, in doing so, they do not find in healthcare institutions an environment that is receptive to such questioning, or willing to help them navigate other information they have obtained by themselves. Vaccination dissent is thus more a point of arrival than a point of departure, more a process than a stance, more the outcome of a pattern of interaction than the expression of an individual decision grounded in a static position from the start.

- **Vaccine uptake drivers, social responsibility and the "free-ride" argument**

Most vaccine-decliners and partial vaccine-decliners interviewed by Cunha and Durand [65] held provisional rather than firm definitive views on vaccine issues. They were open to reconsidering these views. Vaccinating for the benefit of society, however, is not a primary driver of such reconsideration -- any more than it is a driver of uptake for vaccine acceptors [9]. Moral judgements and imputations of selfishness are therefore misplaced and do not promote vaccine acceptance. Moreover, they are actually counterproductive in that they can induce or crystallize a defensive anti-vaccine position. This counterproductive effect runs parallel to the authoritarian frames of communication mentioned above, alienating rather than promoting parents' trust.

The issue of coexistence of children with different immunisation status (the co-presence of vaccinated and non-vaccinated children in schools, for example), or of the tension between individual freedom of choice and collective safety is considered by these parents on three specific levels. Firstly, it is considered (by reticent vaccine-acceptors, vaccine-decliners and vaccine-undecided or partly decliners) in terms of concrete communities, such as the schools attended by their children. Coexistence is negotiated (sometimes with the mediation of school boards) by reversing the positions of risk i.e. these parents hold that it is not unimmunised children who present a potential threat to immunised ones, but the other way round.

Secondly, coexistence is also considered at the level of public health, weighing notions of personal freedom and the security of others. However, the security of others is framed in terms of concrete individuals, not collective abstractions, such as "society": "[to vaccinate] is a matter of social responsibility... We have a neighbour who is pregnant. If an unvaccinated kid was to be around, and if she got rubella ... If I was pregnant, I wouldn't like that either... That was one of the things that made us change our mind and to eventually vaccinate our kids."

Thirdly, also at the level of public health, the principles of individual freedom and collective security are on occasion considered in wider and more abstract terms. However, even at this level the negotiation of such principles remains context specific, dependent on events such as exceptional disease outbreaks, or changing circumstances such as the evolution of herd immunity. Used to being confronted with the "free ride" argument (others vaccinating give non-vaccinators the possibility to benefit from herd immunity and avoid personal risks), these parents present their option as harmless for others while not risk-free for themselves in the present; also, they present it as reversible in the

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of doctor's conduct only. Moreover, it has to be put in the wider context of Portuguese history. The very idea of health as a right pertains to a welfare state that saw its inception only after the democratic revolution of 1974. The long authoritarian regime to which this revolution put an end was not without leaving its marks on the political culture of everyday citizenry (Cabral 2000). Questioning (medical) authority -- and accommodating that questioning -- is also one among other changes in that culture.

future, as an on-going negotiation with collective circumstances: “People should not be required to vaccinate themselves in all circumstances. If suddenly it is necessary to vaccinate for public health reasons (in case of epidemics), then OK.”

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5. Determinants of non-vaccination by UVG

In this table, the identified determinants found in all UVGs are listed. For each determinant and each UVG, we assessed the significance of each determinant (not so important / quite important / very important) in determining vaccination acceptance/uptake, based on all the evidence reviewed.

Table 1. Determinants of non-vaccination by UVG

Determinants[11] *+ not so important in refusing vaccination* *++ quite important in refusing vaccination* *+++ very important in refusing vaccination*	**Anthroposophists**	**Orthodox Protestants**	**NVKP**	**Roma community**	**Macrobiotics**	**'Critical citizens'**
Severity, safety and effectiveness						
• Perceived severity of VPD						
- Different severity of VPD (measles/mumps/rubella vs. polio)	+++	+	+	+		+
- some VPD are useful for child's development	+++				+++	
• Perceived severity AEFI						
- Fear about side effects	++	+	+++	+		++
- Negative effect/aggressiveness of the vaccine	+++		++		+++	+
- Multiple simultaneous vaccines increase risk of side effects	+++					++
- Vaccines cause illnesses, damages, or even death			+++	+	+++	
• Perceived susceptibility to VPD						
- Fear of the disease (depends of the severity of the VPD, measles/mumps/rubella vs. polio)	+++	+			++	+
• Perceived susceptibility side effects	++		+++		++	+
• Perceived efficacy of vaccination						
- Doubts about the effectiveness of the vaccination	++	+	++	+	++	+
• Components of the vaccine could be dangerous (poisons, toxins, contaminants)	+++		+++		+++	+++
• Anticipated regret of not being vaccinated if the child gets the disease	++					+++
• Previous bad experience with vaccination (self or other)			+++			+
Flexibility / freedom						
• Monovalent (single-antigen) instead of combined vaccines	+++					+++
• Individual adapted vaccination schedule (time, dose…)	+++					+++
• Parental choice, want to decide themselves	+++	+	+++		+++	+
• Mandatory vaccination (for school) / negative sanctions in case of no vaccination				+++		+

[11] Assessment of the importance in refusing vaccination based on our knowledge

Knowledge						
• Lack of knowledge about vaccination (vaccination schedule, VPD, complications of VPD, potential risks of vaccination, vaccine components & effectiveness)				++		
• Lack of detailed scientific information (from IPH)	++					+++
• Lack of knowledge about how to get the vaccine (where, by whom …)				++		
Cultural aspects						
• Alternative medicine					+++	+
- Homeopathy	+++		+		+++	+
- Natural treatment	+++		+		+++	+
• Religious beliefs - vaccination is against God's will		+++		+		
• Natural life style	+++		+	++	+++	+
Practical issues						
• Poor access to Healthcare Centre				+++		
• Vaccine cost (if single-antigen) / indirect costs (transport)	+			+++		
Social influence, perceived norms						
• Influence by family, community, tradition	+	++		++		
Dialogue with physician, child health centre						
• Lack of available / accessible information about VPD and vaccination	++		++	++		+
• Insufficient time to discuss and debate about vaccination	++					+++
• Acceptance of their choice by the HCW / perceived discrimination / medical authority	++		++	++		++
Search for truth						
• Mistrust government (government, MoH)	+		+++	+	++	
• Mistrust scientific experts (IPH)	+		+++		++	+
- Not enough information about vaccination, risks, components of vaccines, side effects …			+++			+
- AEFI are underreported			+++		+++	+
- Insufficient research is done (on vaccination, AEFI ...)	+		+++			
Mistrust pharmaceutical industry	+		+++		+++	++
- Conflict of interest / pharma profiting from vaccine use	+		+++		++	

6. Theoretical vaccination behaviour model

Above the factors of vaccine-uptake have been identified among the UVGs. To know which determinants are most important in changing the vaccination intention and/ or behavior and how the determinants are related to each other a vaccination behavior model should be developed. Below we describe an existing theoretical vaccination behavioral model for the general Dutch population just as an example.*

6.1 Existing theoretical vaccination behavior model for the general population in the Netherlands

Paulussen et al.* examined the factors that influence parents' decisions to have their children vaccinated under the Dutch NIP. The framework of this study was mainly derived from the Theory of Planned Behaviour**, the Social Cognitive Theory*** and the elaboration likelihood model****. Additional concepts were incorporated on the basis of insights from previous research and theory-based hypotheses. The theoretical framework is presented in figure 1. This framework suggests that individuals' behavioral intentions are a result of attitudes toward the behavior in question, social influences and self-efficacy. These are the proximate determinants. Proximate determinants have the most direct effects on behavior. Besides attitude, which is the overall evaluation of vaccination for the diseases covered by the NIP, a distinction was made between three attitude-related constructs: risk perception, outcome expectations and anticipated regret. Furthermore, this framework also suggests that knowledge of content NIP and the diseases, experience with the disease, level of information processing and social demographics (e.g. ethnicity, educational level) might influence vaccination behavior. The latter factors are called distal determinants. Distal determinants are derived from the macro-level sociocultural and environmental context, and are often described as background factors that predispose people to greater or lesser health risks. Examples include ecological setting, demographic features, political economy, social structure and cultural patterns. Distal determinants are expected to influence behavior only via the proximal determinants.

It should be noted that for the general population in the Netherlands only general attitude, self-efficacy and outcome expectations were significantly associated with vaccination intention. The attitude component appeared to be the best predictor of intention. When looking more into detail which determinants influenced attitude most, results showed that it was most strongly influenced by outcome expectations, risk perception and anticipated regret.

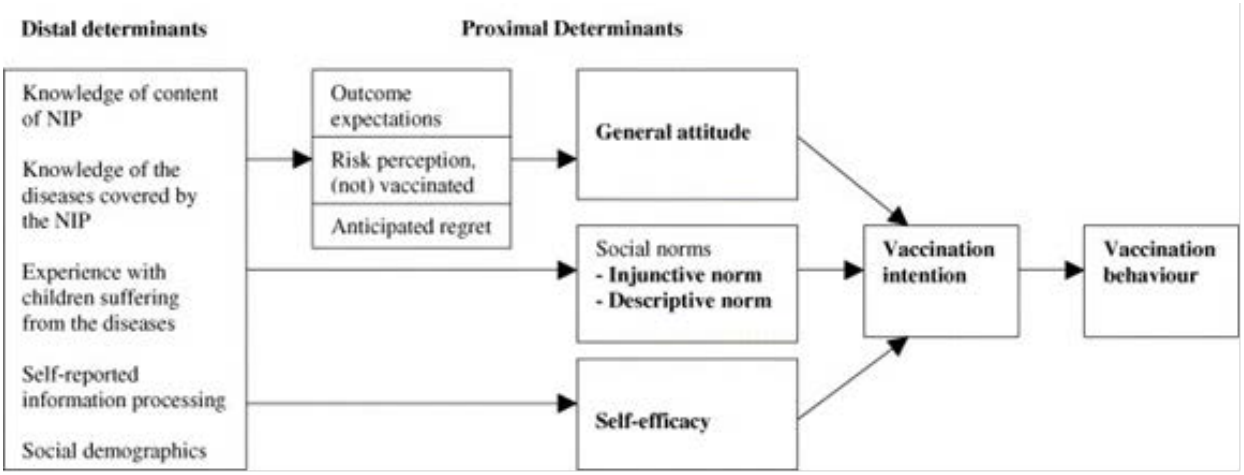

Figure 1. Theoretical framework

*Paulussen TG, Hoekstra F, Lanting CI, Buijs GB, Hirasing RA. Determinants of Dutch parents' decisions to vaccinate their child. Vaccine 2006;24(5):644-51. Epub 2005 Aug 26.
**Ajzen I. The Theory of planned behaviour. Org. Behav. Hum. Decis. Process. 1991; 50:179-211.
***Bandura A. Social foundations of thought and action: a social cognitive theory. Prentice-Hall, Englewood Cilffs (1986).
****Petty RE, Cacioppo RT, L. Berkowitz (Eds.). The elaboration likelihood model of persuasion. In: Advances in experimental social psychology, Academic Press, New York (1986), pp. 123–205.

Proposed additions to the model for under-vaccinated groups

As some of our determinants listed in table 1 in chapter 5 were not included in the framework described above (Figure 1), we propose here an additional model (Figure 2) with the following determinants included: cultural aspects, freedom, trust, dialogue with physician and practical barriers. Cultural aspects are included as a distal determinant while all the others are proximal determinants. It should however be noted that this model has not been tested and that quantitative research for each of the UVGs is needed in order to identify which determinants are significantly associated with vaccination intention and behavior.

A new theoretical behavior model might be soon published based on Dutch questionnaire data among parents with child aged 0-4 years old by Irene Harmsen (see also chapter 7 of thesis: http://digitalarchive.maastrichtuniversity.nl/fedora/get/guid:072c7383-8a0a-4d67-87cb-615c3217b5f5/ASSET1).

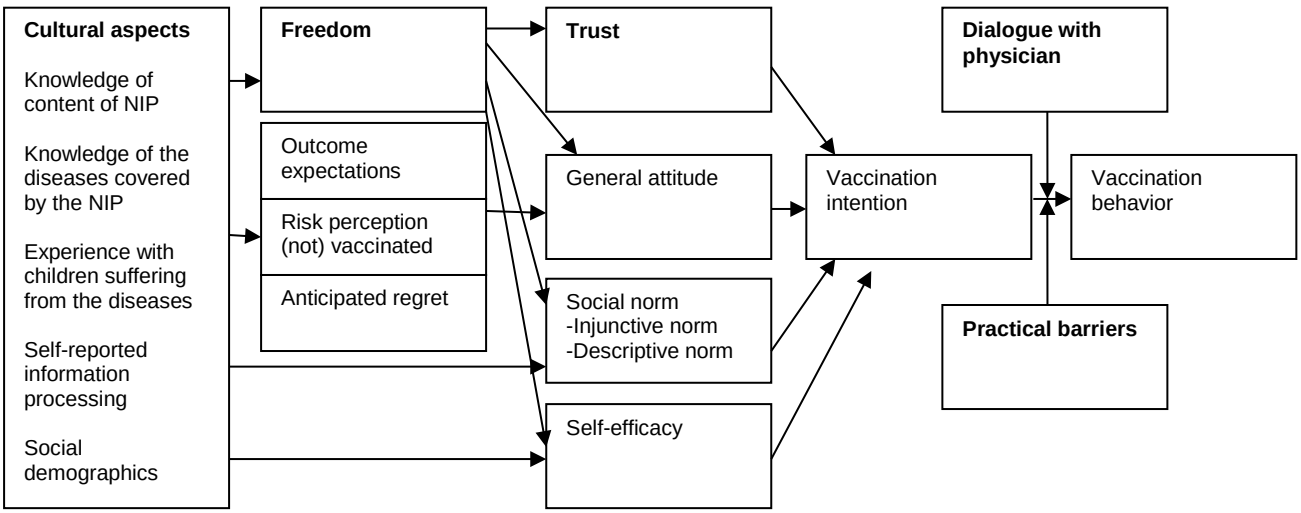

Figure 2. Extended theoretical model

7. Determinants and performance objectives

Through the development and implementation of communication strategies, UVGs will be provided with relevant information and support in order to make a well-considered vaccination decision. It is envisaged that this will impact positively on their decision to vaccinate if vaccines are advocated in a major outbreak setting.

In the previous chapters, we showed that there are common key determinants between different UVGs and that not all members within a specific group necessarily share the same ideas (i.e. intra-group commonalities and within-group heterogeneity). Therefore, it seems more relevant to develop communication strategies by focusing on determinants of poor vaccine uptake rather than on specific UVGs.

The matrix presented in chapter 7.4. is part of the second step of the IM approach (3.2.2). It crosses performance objectives (rows) with the selected determinants (columns) where programme objectives (cells) were defined in order to accomplish these performance objectives [13]. We defined performance objectives by determinant, by considering the following questions: what exactly do we want to do, change or improve concerning vaccination among these UVGs in case of major outbreaks? The programme objectives state what needs to be achieved in order to accomplish the performance objectives. The main output of this matrix is the DPOM tool, also presented in chapter 11 with SMART objectives (Specific Measurable Achievable Relevant Time-based) on which CBI tactics are based.

7.1 Selection of determinants of poor vaccine uptake

Some of the determinants listed in table 1 in chapter 5 are very difficult to change or not changeable at all (i.e. religious arguments). To develop our tool, we selected the determinants that were shared by at least four UVGs out of six and on which intervention and more effective communication is possible:

i. Perceived severity of the disease and its possible complications
ii. Safety of the vaccine
iii. Effectiveness of the vaccine
iv. Dialogue with HCW
v. Trust in government and health authorities.

The determinant about the freedom of parental choice in relation to vaccination was not selected for the matrix because we cannot advise IPH on national vaccination programmes, although we think that this determinant is of importance. We want to develop communication strategies to communicate with parents in a trustworthy manner. Communication tactics have to take into account parents' beliefs concerning vaccination, and give them all necessary information to make a well-considered decision about vaccination.

The determinants about natural lifestyle, natural treatment and homeopathy were also not selected. We recommend the development of communication strategies to talk about vaccination and convince people about its benefits. We do not want to compare vaccination with natural alternatives. In addition, to have natural lifestyle or treatment is not a barrier to being vaccinated, it should be positioned as being complementary.

7.2 Definition of performance objectives

Performance objectives were defined for the communication strategies. A performance objective is a statement of a specific desired end-result/ goal: what does the IPH want to achieve as performance objectives in order to change the UVGs determinant of behaviour.

We defined the following performance objectives:

(i) Ensure lack of information is not a barrier to vaccine uptake: give UVGs all relevant information they need about vaccines and vaccine-preventable diseases.
(ii) Ensure parents/caregivers have support to make an informed decision about vaccination: with the information provided, help parents and others to make a well-considered decision to get the vaccination or not.
(iii) Ensure lack of access is not a barrier to vaccine uptake: give all details and information on how to get access to vaccination (recognising that some of these populations are mobile)
(iv) Emphasise recommended prevention measures to prevent family and others from contracting the disease (such as good hand hygiene, relevant exclusions from work/ school/ nursery)*

*Knowing that several groups/individuals will not vaccinate, we stress the importance of other preventive measures for acquiring and transmitting the disease

7.3 Definition of programme objectives to accomplish the performance objectives

To accomplish the performance objectives described above, we need to define programme objectives for each determinant. The following matrix crosses performance objectives with selected determinants and within each cell the programme objectives that need to be achieved. These should provide an answer to the question "what do UVGs need (from IPH) with regard to a specific determinant in order to accomplish the performances objectives"?

For example, about their doubts/concerns/questions about the severity of the vaccine-preventable disease and its possible complications:

- In order to provide them all needed information and to answer all questions they have about the disease, it seems necessary to:
  - Provide complete data on the severity of the disease, its transmission, its symptoms and its possible complications etc. Some examples showing consequences of getting the disease could be provided.
  - Make sure it is understandable and clear, and in a form accessible to those with poor literacy skills
- In order that they can make a well-considered decision, it is necessary to:
  - Make sure they have correct/sufficient/enough knowledge about the disease and the vaccine
  - Interpret, compare and verify whether they have all info they need to make the decision
  - Be sure they are aware of advantages and disadvantages of vaccination.
- In case they decide to vaccinate:
  - Make sure they have enough information about the severity of the disease to support their motivation to vaccinate
  - Provide all information on where, how to get the vaccine, how many shots, cost etc.
- In case they do not want to vaccinate:
  - Advice and tools can be provided to try to limit the transmission of the disease (do not stay in overcrowded area, washing hands etc.)

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7.4 Determinants and Performance Objectives Matrix

Table 2. Determinants and performance objectives matrix

Performance objectives UVGs:	Determinants				
	Perceived severity of the disease and its possible complications	**Vaccine safety**	**Vaccine Effectiveness**	**Attitude of HCWs**	**Trust government and Health authorities**
Have all the information they need	- Provide complete data on the severity of the disease, its transmission, its symptoms… and possible complications (with examples) - Make sure it is understandable for all (literacy, language)	- Provide complete data on how the vaccine was made, list of components, clinical-trials and all tests that were done, side effects - Make sure UVGs understand risk and benefits	- Provide complete data on all studies that were done on vaccinated vs. non vaccinated - Make sure UVGs understand the effectiveness of both preventive action and treatments	- Make sure UVGs feel confident to have discussion with HCWs - Ensure HCWs have the tools they need (ECDC toolkit) and know how to communicate with different groups	- Demonstrate transparency in various steps of the vaccine: introduction into schedule, procurement etc. (Pharmaceutical contracts, components of the vaccine…)
Making a well-considered/informed decision (vaccination or not)	- Interpret, compare and verify whether the UVGs have all info they need to make the decision re severity. - Make sure UVGs have enough information - Make sure UVGs know the advantages > disadvantages of the disease	- Interpret, compare and verify whether they have all info they need to make the decision re safety. - Ensure UVGs are confident and have enough information - Ensure UVGs are aware of advantages > disadvantages	- Interpret, compare and verify whether they have all info they need to make the decision re effectiveness. - Are confident having enough information - Aware of advantages > disadvantages	- HCWs are aware of UVGs and their beliefs - HCWs know how to identify UVGs and their beliefs - HCWs have access to communication tools	- Demonstrate that there is government integrity in communication related to severity, safety and effectiveness of vaccines

Get the vaccination	- Make sure UVG's have enough information on severity of the disease - Provide information on where to get the vaccine, what the costs are, how many shots are needed …	- Ensure UVGs are confident having enough information on vaccine safety	- Ensure UVGs are confident having enough information on VE	- Having a positive attitude toward vaccination and be able to communicate about vaccination with confidence	- Taking the vaccine is the best thing to do, no other conflicts of interest
Take prevention measures	- Provide advice and tools to try to reduce transmission of the disease (good hand hygiene, relevant exclusions from work/ school/ nursery …)	- Continue to confirm the safety of the vaccine	- Continue to confirm the VE	- Have a positive attitude to the preventive measures recommended and be able to communicate them with confidence	- Explain prevention measures taken by the government at a national level, by IPH at a regional level….

The same matrix with measurable programme objectives (SMART matrix) to achieve is presented in Part II.

Part II: Communication and behavioural influence tactics recommendations

8. Introduction and approach taken to this section of the report

This section of the report supplements the DPOM tool with a set of possible communication and behavioural influence (CBI) tactics. The aim of this section is to illustrate how the DPOM Tool can be used to develop health promotion interventions for UVG's and other segments of the population. The CBI tactics suggested have been drawn from or influenced by suggested actions set out in key national and international reviews of evidence and practice which are detailed below.

9. Key Communication Reference

The recommendations contained in this section of the report for communication action, and action directed to influencing behaviour amongst UVG's in Europe prior to, after and during an outbreak are drawn from the following sources: the behavioural analysis set out in WP3 of the E-com@EU[12], findings and recommendations from the EU Seventh Framework Programme funded 'Tell Me 'project, specifically reports; D1.2 Review of Crisis Communications and report[13] and D1.3 Segmentation and Specific Communication Needs of Target Groups[14]. Other key reference papers that set out recommended, and where the evidence exists recommendations about effective and efficient strategies, that have been used to develop the communication interventions associated with pandemic events and immunisations in particular set out in this paper are listed in the Appendix 14.4.

[12] E-Com@EU Programme Work Programme 3. Report on Behavioural Analysis. From Communication to Behavioural Influence, an Overview of Approaches and Issues

[13] D1.2 Review of Crisis Communications TELL ME project – GA: 278723

[14] D1.3 Segmentation and Specific Communication Needs of Target Groups TELL ME project – GA: 278723

10. Summary of what we know about influencing behaviour

A summary of what is known about influencing knowledge, attitudes, and behaviour has been set out in the behavioural review of WP3 of the E-com@EU project. This summary is repeated below to give the context within which the tactics suggested for each of the cells in the DPOM tool developed by WP6 can be validated. Recommendations that flow from these conclusions are set out in Appendix 14.3.

Key Conclusions:

(i) **The complex behaviour challenges associated with pandemic events highlight the limits of conventional communication approaches.**

Well researched, well planned and targeted communications programmes are a vital part of all pandemic management and control intervention programmes. However, the tendency to rely on simplistic information transmission and processing models of influence can reduce the impact of these programmes. Some of the new social policy and health tools that behavioural scientists and others working in the field of behaviour influence have developed, based on a growing body of behavioural research summarised in books such as; Thinking Fast and Thinking slow[15], Nudge[16] and Influence[17], have generated a lot of interest amongst many policy makers and planners in government health sector organisations. This new work confirms and makes accessible the understanding that a much wider range of human motivations exist than just rational self-interest based on logical information processing. This new understanding makes clear the need for strategies of influence that go beyond the transmission of factually accurate logical information as the main way to influence behaviour and opinion prior to, during and after pandemic events.

(ii) **Multiple interventions are more successful.**

The effectiveness of single interventions in isolation does not appear to be as great as combining ones that impact on conscious decision making, and decisions that are influenced by other mental processes and external factors such as social norms and incentives. Economic instruments can provide the stimulus for change with communication and choice editing shaping successful uptake. (See separate report under WP3 focused on incentives)

(iii) **Humans are not entirely rational when making health choices and this understanding needs to be reflected in pandemic programmes.**

Individuals do not simply decide on the basis of well-presented information to act in way that demonstrates that they have carefully considered the costs and benefits of an action and then selected the option that results in maximum personal or family benefit. Instead, there are numerous internal and external influences on an individual's behaviour that need to be considered and influenced. If we are to influence health behaviour we need to apply a more sophisticated approach to understanding and developing more comprehensive strategies to influence behaviour that include, but go beyond the transmission of scientifically accurate information, influencing strategies that target non-rational choice. There are clearly considerable ethical issues associated with such approaches that will need to be considered.

(iv) **Behavioural models and theory can help strengthen the development delivery and evaluation of pandemic communication and behavioural programmes.**

[15] Kahneman D, Thinking fast and thinking slow Macmillan. 2011.
[16] Thaler R & Sunstein C, *Nudge: Improving decisions about health, wealth and happiness,* Penguin 2009
[17] N. Goldstein; S. Martin; R. Cialdini. *Yes! 50 Secrets from the Science of Persuasion*, Profile Books 2007

One of the tentative conclusions that can be drawn from this review and the work of WP3 is that theories intended to modify individual level behaviours remain a central focus in pandemic events. Policy and training interventions could be developed to broaden this focus to include ecological theory and models to guide research, intervention design and evaluation. When constructing behavioural interventions the use of several theories and models appears to assist with identifying the key elements which are of most use in either explaining the behaviour or predicting what will influence change. This understanding can be used as the foundation around which communications and messaging can be designed, and other forms and types of influence developed. This is the approach Darnton recommends to policymakers[18]. There will be occasions however, when existing behavioural theory is not available or appropriate. In these circumstances, it will be necessary to use existing theory and models to build a behavioural framework from scratch to inform programme planning design and evaluation.

(v) **It is not sufficient to consider an individual's voluntary behaviour change in isolation.**
The impact of social, economic and environmental factors have a large influence on people's ability to behave in certain ways and their motivation to do so. The behaviour of others and the general cultural and social environments expressed through notions of social capital and community resilience also needs to be considered and often targeted if individuals are to be helped to sustain a positive behaviour or modify a less healthy behaviour. The role of communication and other forms of behavioural influence such as nudging outlined in this paper focus mainly on changing 'voluntary' behaviour, rather than enforcing behaviour change. However, governments supported by public health institutions in some outbreak situations will need to use tools to 'enforce' rather than encourage behaviour change. It needs to be recognised that when the health threat is great governments may need to use different tools to influence people to become compliant including incentives and or sanctions. The use of such tools will also need to be accompanied by communication and behaviour change programmes that seek to engage, explain and involve people in the execution of such non-voluntary change interventions such as fines or restrictions of movement or assembly.

[18] GSR Behaviour Change Knowledge Review. Overview of Behaviour Change Models and their Uses. Briefing Note for Policy Makers. Darnton A. Centre for Sustainable Development, University of Westminster 2008.

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11. The Hypothesis inherent in the Determinants and Performance Objectives Matrix Tool

The inherent hypothesis of this approach is that a determinant-based approach may be more effective and efficient than a segmented approach based on specific sub-groups of the population such as the OPDs, Anthroposophists and Roma communities. The potential efficiency of the programme may be significant given that such an approach could also be used with the general population. What is not being advocated is a total disregard for the specific needs of specific segments of the population that resist actively or passively immunisation uptake. Rather the use of a determinants-based approach may augment and enhance more specifically segmented and targeted approaches based on specific sub-group characteristics.

The DPOM tool set out below (table 3) is derived from the matrix presented in chapter 7.4 (table 2). We defined a SMART matrix. A SMART matrix is a communication and planning tool used to identify the specifics of actions. SMART stands for specific, measurable, attainable, resources, and time:
Specific: The objectives should clearly state exactly WHAT has to be accomplished by whom and for whom.
Measurable: The objectives should clearly state the LEVEL of accomplishment of end-results based on ones needs. This element of an effective objective utilizes quantitative and qualitative measures.
Attainable: Is it realistic to expect completion of this objective as it is written?
Realistic: The objectives should be realistic. The results, or improvements expected, are possible to achieve.
Time: The performance objective should be accomplished within a certain time period.

This DPOM is a standalone tool that can be used by public health professionals and others responsible for planning, delivering and evaluating communication and behavioural influencing programmes associated with the response to pandemics and other significant outbreaks.

In order to illustrate how this matrix could be applied to develop communication and behavioural influencing interventions the following sections of this paper set out possible communication interventions for each of the 20 cells of the matrix. The interventions suggested are taken from the reviews cited at the beginning of this part II of the WP6 report. One of the key issues - as pointed out by the World Health Organization (WHO), ECDC and Centre for Disease Control and Prevention (CDC) and summarised in the introduction of this part - is that effective programmes tend to consist of a mix of interventions that include both communication initiatives and a mix of other behavioural influence strategies and structural factors such as making services accessible and low cost so as to enable easily access to support and remove barriers to adopting preventive and treatment behaviours. Therefore, the communication approaches that are set out here are not presented as a total and complete set of interventions; rather they are illustrative of just the communications component of a fuller programme. A final warning regarding the communication interventions set out and the use of these relates to the need to inform the selection of interventions by the use of research about beliefs attitudes and factors among the population that may impact on vaccine uptake or reaction to specific communication interventions. As recommended in WP3 those responsible for developing and delivering interventions need to develop robust insight research to help them select the most effective and efficient interventions and that all possible interventions should be field tested prior to full implementation. This implies the need for on-going developmental work prior to pandemic emergencies.

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Table 3. The determinants and performance objectives matrix (SMART matrix)

Performance objectives UVGs:	Determinants				
	Perceived severity of the disease and its possible complications	**Vaccine safety**	**Vaccine Effectiveness**	**Attitude of HCWs**	**Trust in government and Health authorities**
Have all the information they need	IPH provides existing data (by literature review, experts, outbreak data) on: - severity of the disease - symptoms - possible complications - differentiated disease and complication risk by age and high risk groups 90% of individuals of the UVGs have access to the information As soon as possible and at least weekly update during the outbreak Cell 1	IPH provides existing data (literature review, reports on all studies that were done) on: - vaccine production - list of vaccine components - clinical-trials and clinical tests - possible side effects - risk analysis for protection and side effects 90% of individuals of the UVGs have access to the information As soon as possible, but at least at start of vaccination, at least monthly update during the outbreak. Cell 2	IPH provides existing data (literature review, reports on all studies that were done on VE (VE in % for various age groups) 90% of individuals of the UVGs have access to the information As soon as possible before vaccination, at least monthly update during the outbreak. Cell 3	HCW (involved in vaccination) know the beliefs of the different UVGs (IPH should provide data on beliefs and how to communicate with these groups -> this report) HCWs use each individual healthcare consultation as an opportunity to discuss vaccination concerns with people from UVGs who do not vaccinate. Before and during the outbreak. Cell 4	IPH starts and maintains a relationship with (leader) members from UVGs Government and health authorities show transparency in all steps of the vaccine development & procurement: - pharmaceutical contracts - Components of the vaccine - give all available information of the epidemiology of the disease (number of cases, mortality rates). Before and at least weekly update during the outbreak and also after the outbreak. Cell 5

Performance objectives UVGs:	Determinants				
	Perceived severity of the disease and its possible complications	**Vaccine Safety**	**Vaccine Effectiveness**	**Attitude of HCWs**	**Trust in government and Health authorities**
Making a well-considered/informed decision (vaccination or not)	UVGs are able and willing to interpret, compare and weigh the risks versus benefits of vaccination (including disease severity, numbers of severe cases, case fatality rate). HCWs discuss the information with individual members of UVGs to enable an informed decision. Before and during the outbreak. Cell 6	UVGs are able and willing to interpret, compare and weigh the risks versus benefits of vaccination (including vaccine safety). HCWs discuss the information with individual members of UVGs to enable an informed decision. Before and during the outbreak. Cell 7	UVGs are able and willing to interpret, compare and weigh the risks versus benefits of vaccination (including VE). HCWs discuss the information with individual members of UVGs to enable an informed decision. IPH ensures that information on VE is accessible to UVGs (literacy, language, population mobility etc.) Before and during the outbreak. Cell 8	HCWs take time to discuss the decision, using available communication tools where needed. HCWs discuss VPD & vaccine information with individual members of UVGs. HCWs don't stigmatise/ judge UVG members for non-vaccination. Before and during the outbreak. Cell 9	Where vaccination is voluntary, government and health authorities communicate that message, but also the need for the choice to be well-informed. IPH discusses decision with key leaders/members of the UVGs Before and during the outbreak. Cell 10

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Performance objectives UVGs:	Determinants				
	Perceived severity of the disease and its possible complications	**Vaccine Safety**	**Vaccine Effectiveness**	**Attitude of HCWs**	**Trust in government and Health authorities**
Get the vaccination	IPH ensures that information on risks/ benefits is accessible to UVGs (literacy, language, population mobility etcetera) IPH informs the UVGs where to get the vaccine (by whom, appointment or not, how many shots) and makes it possible for the UVGs to easily get the vaccine. IPH ensures invitations to, and reminders for vaccination ('call/recall' messages) are accessible to UVGs (e.g. literacy, language, population mobility) Before and during the outbreak. Cell 11	IPH ensures that information on vaccine safety is accessible to UVGs (literacy, language, population mobility etcetera) IPH informs the UVGs on where to get the vaccine (by whom, appointment or not, how many shots) and makes it possible for the UVGs to easily get the vaccine IPH ensures invitations to, and reminders for vaccination ('call/recall' messages) are accessible to UVGs (e.g. literacy, language, population mobility) Before and during the outbreak. Cell 12	IPH ensures that information on VE is accessible to UVGs (literacy, language, population mobility etc.) IPH provides detailed info to UVGs on: where to get the vaccine (by whom, appointment or not, how many shots) and makes it possible for the UVGs to easily get the vaccine IPH ensures invitations to, and reminders for vaccination ('call/recall' messages) are accessible to UVGs (e.g. literacy, language, population mobility) Before and during the outbreak. Cell 13	HCWs recognise that vaccine information and access may be challenging for UVGs (literacy, language, population mobility etcetera), and facilitate this in 'call/recall' for vaccination HCWs address the concerns of UVGs when discussing and administering the vaccine. HCWs explain to UVGs potential vaccine side effects, and how to manage them Before and during the outbreak. Cell 14	IPH monitors and publishes vaccine coverage data Before, during the outbreak and after the outbreak. Cell 15

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Performance objectives UVGs:	Determinants				
	Perceived severity of the disease and its possible complications	**Vaccine Safety**	**Vaccine Effectiveness**	**Attitude of HCWs**	**Trust in government and Health authorities**
Take preventive measures	IPH provides advice and guidance to try to reduce disease transmission: relevant exclusions from work/ school/ nursery, good hand hygiene (washing with soap & water etcetera) / cough hygiene IPH studies risk perceptions among the various UVGs Before and during the outbreak. Cell 16	IPH provides advice and guidance to try to reduce disease transmission: relevant exclusions from work/ school/ nursery, good hand hygiene (washing with soap & water etcetera. / cough hygiene IPH continues to evaluate vaccine safety During and after the outbreak. Cell 17	IPH provides advice and guidance to try to reduce disease transmission: relevant exclusions from work/ school/ nursery, good hand hygiene (washing with soap & water etcetera) / cough hygiene IPH continues to evaluate VE During and after the outbreak. Cell 18	HCWs accept a decision not to vaccinate and provide advice to try to reduce disease transmission (e.g. relevant exclusions from work/ school/ nursery; good hand hygiene, cough hygiene). HCWs continue to discuss about vaccination. During the outbreak. Cell 19	IPH explains prevention measures taken by the government at a national level, by IPH at a regional level and provides advice and guidance to try to reduce disease transmission (e.g. relevant exclusions from work/ school/ nursery; good hand hygiene, cough hygiene) During the outbreak. Cell 20

12. Potential communication and behavioural influence tactics for each of the determinants and performance objectives matrix tool cells

12.1 Performance objective: Ensure parents have all the information they need

Cell 1: Perceived severity of the disease and its possible complications

Communication tactics:

1. Use traditional mass media (TV, radio, newsprint, magazines, and cinema and outdoor advertising) to explain to the public:
    - Symptoms of the disease (what to look out for)
    - Disease severity and assessment of risk to the public using references and graphics that the public can understand, e.g. how likely is the event in terms of a comparison with being involved with a road accident? or how severe is the disease in terms of how many people out of 1000 who contract it will die or become permanently damaged?
    - Make people aware of modes of transmission and preventive measures effective in reducing transmission.
2. Have senior scientists and public health and health promotion officials ready to answer questions and provide guidance. Use traditional media and telecommunications so that concerned members of the public can reach government to share views re severity. Use approaches such as a phone hotline, radio call in line.
3. Use digital media and WWW to both provide official information about severity and to act as a method of tracking online concerns and issues that may need a response from IPH's and government departments.
4. Set up a press and web-based communication channels briefing service for journalists and other content providers of these services regarding disease severity. Distribute daily (or more frequent if necessary) update bulletins.
5. Develop and promote, using all forms of media, a national Q&A service for people with concerns about severity and risks.

Cell 2: Vaccine safety

Communication tactics:

1. Provide information via mass and digital media about vaccine safety: promote this as a sub-component of information about the need to act, possibly via a strap line about vaccine safety on all promotional material.
2. Provide a full online information service focused on safety and quality assurance processes for vaccine production, components, and possible side effects. Also provide open access to clinical trial data and medicines regulatory agencies' reports and reviews.

3. Develop an interactive Risk / Benefits app (cross-platform) that people can use to assess the relative risks and benefits at individual level of taking up or refusing vaccination. There could be links form such an app to population level risk assessment apps that model population level impacts of individual actions.
4. Develop and promote online discussions and webinars (web seminars) featuring leading local/ national experts on the evidence about vaccine safety and the effectiveness of vaccines and other preventive measures.
5. Work with commercial and state TV and radio providers and mass print media such as newspapers to develop feature programmes and articles about risks versus benefits (VPD and vaccine).

Cell 3: Vaccine effectiveness

Communication tactics:

1. Have a credible (in the opinion of the public, media and UVG assessed by prior market research) spokesperson who provides information to the public about the effectiveness of the vaccine and other interventions that are being recommended.
2. Release in a planned and on-going way prepared statements to support the effectiveness of the vaccine via news releases, and articles in traditional and digital media.
1. Consider direct mail shots to households focused on specific issues related to the severity of the disease and the effectiveness of the vaccine in preventing disease/ attenuating severe disease, as well as when and how to get vaccine and what people can do to prevent spread of infection and care for those who fall ill. In the case of mobile populations such as sections of Roma communities, deliver materials of suitable readability and style delivered directly to camps.
2. Respond to public and media questions about VE openly and rapidly via a specialist information hub, ideally one that has been planned for this purpose in advance of an event, delegated for this purpose. Credibility and future trust hinges on early, accurate and honest reaction and response to an outbreak.
3. Do not use mass and digital media to stress the safety of vaccines, rather frame messages in terms of protection (against infection) and its loss. Use message strategies that are understandable and compelling. Use (mild) fear as well as positive protective messaging to reinforce the campaign.

Cell 4: Attitude of HCWs

Communication tactics:

1. All frontline HCW who have direct contact with the public should be provided with summary snapshots of what is known about the attitudes and beliefs of people who are being encouraged to take up the vaccine including the views and beliefs of UVG's.
2. All frontline HCW who have direct contact with the public should be provided with scripts, questions (e.g. FAQs) and phrases that may help people make informed

decisions about uptake or rejection of the vaccine. These scripts should cover both starting and progressing conversations about vaccination.

3. Provide (ideally before an outbreak) regular staff training and development to healthcare staff who have an opportunity to offer / recommend vaccine on insights about population views and beliefs and how to communicate about these using tested scripts, phrases and questions (e.g. as part of new staff induction, routine staff training, staff professional development etcetera).
4. Provide HCW who will be having conversations about vaccination with a simple way to log and report the audience segment, issues raised and the outcome of the discussion. This material can be used to track concerns and issues that may need further explanation, and the impact of such conversations.
5. Use digital and targeted mass media such as professional journals and magazines to set out guidance and testimonials about the importance of developing and sustaining trust by HCW. Use trusted spokespersons that the HCW can relate to and like.

Cell 5: Trust in government and health authorities

Communication tactics:

1. Establish on-going dialogue with key opinion formers and leaders of UVG's. Develop an on-going relationship plan for each UVG identified locally/ nationally
2. Arrange for regular briefings for opinion formers and leaders of UVG's prior to, during and after any outbreak/ incident.
3. Provide, via the WWW, a transparent account of issues such as vaccine development, safety tests, possible side effects and assessments of the level of protection provided.
4. In a major outbreak, provide to the UVG and the general population a continuous sharing of information about developments with daily news updates. Invite the public and UVG to provide feedback and raise questions. Form a staffed 24 / 7 Question and Answer team to assist media and news teams, professionals and the general public. Consider also using social media sites (Twitter, Facebook etcetera) to provide regular updates.
5. Use mass media and digital media to present testimonials from trusted sources such as GPs, Public Health leaders and if possible members of UVG's to promote trust in the public health service and measures being recommended and taken.

12.2 Performance objective: Making a well-informed decision (to vaccinate or not)

Cell 6: Perceived severity of the disease and its potential complications

Communication tactics:

1. Develop decision guides for UVGs and the general public setting out risks versus benefits, including disease severity and potential consequences of being unvaccinated. These guides should include frequently asked questions (FAQs) with answers, and illustrations of risk and consequences framed in ways that are relevant

to and understandable by UVG's, as well as accessible (literacy, language etcetera). These guides should be made available in paper form and through digital technology such as websites and (cross-platform) App's.

2. Direct mail and distribution of targeted guidance with information about how to access vaccines in the NIP or in an outbreak setting, and other available preventive measures. This material should include factsheets and information brochures and posters. Information materials should also be made available via digital platforms. For those with low literacy levels HCW should provide talks and presentations to community groups and UVG's about the assessment of the severity of the threat. Radio and TV should also be used.
3. A 'call system' for parents who may be reluctant or unsure about vaccination should be offered online and via a telephone assistance scheme with interactive triage to address questions and doubts that they may have about the severity of the disease. Those needing face-to-face consultations should be directed via online systems to an appointment with a local HCW. There should also be an open-access drop in consultation service that is provided at easy to reach locations and open at convenient times. Outreach decision aid sessions should also be offered in locations such as community centres, kindergartens, playgroups and schools.
4. HCW should be provided with materials and a structured and assessed training programme to help them initiate discussions and answer parents' questions about severity of the disease and the risks of being unvaccinated or of not taking other preventive measures.
5. Use mass media and digital media to encourage parents and care givers to have a conversation about disease severity and risk concerns with a HCW; and how to access such a consultation.

Cell 7: Vaccine safety

Communication tactics:

1. Decision guides should be produced for UVG and the general public, setting out details about the safety of vaccines offered in the NIP, including in an outbreak setting i.e. country-specific information. These guides should include frequently asked questions (FAQs) with answers, and illustrations of risk and consequences framed in ways that are relevant to and understandable by UVG's, as well as accessible (literacy, language etc.). These guides should be made available in paper form and through digital technology such as websites and (cross-platform) App's.
2. Direct mail and distribution of targeted guidance regarding the high level of safety of vaccines in the NIP and other preventive measures should be made widely available. This material should include factsheets and information brochures and posters. Information materials should also be made available via digital platforms. For those with low literacy levels HCW should provide talks and presentations to community groups and UVG's about the safety of NIP vaccines.
3. Parents who may be reluctant or unsure about accepting vaccination should be offered online or telephone interactive triage to address questions and doubts that

they may have about vaccine safety, as part of a 'call system'. Those needing face-to-face consultations should be directed via online systems to an appointment with an HCW. There should also be an open access drop in consultation service that is provided at easy to reach locations and open at convenient times. Outreach decision aid sessions should also be offered in locations such as community centres, kindergartens, play groups and schools.

4. HCW should be provided with materials and a structured and assessed training programme to help them initiate discussions and answer parents' questions about vaccine safety or other preventive measures.
5. Use mass media and digital media to encourage parents and care givers to have a conversation about vaccine safety and risk concerns with a HCW; and how to access such a consultation.

Cell 8: Vaccine effectiveness

Communication tactics:

1. Decision guides should be produced for UVG and the general public, setting out details about the effectiveness of vaccines in the NIP, including in an outbreak setting i.e. country-specific information. These guides should include frequently asked questions (FAQs) with answers, and illustrations of how effective the vaccines are. Messages should be framed in ways that are relevant to and understandable by UVG's, as well as accessible (literacy, language etcetera). These guides should be made available in paper form and through digital technology such as websites and (cross-platform) App's.
2. Direct mail and distribution of targeted guidance regarding the effectiveness of vaccines in the NIP and other preventive measures should be made widely available. This material should include factsheets and information brochures and posters. Information materials should also be made available via digital platforms. For those with low literacy levels HCW should provide talks and presentations to community groups and UVG's about the effectiveness of NIP vaccines.
3. Parents or care givers who may be reluctant or unsure about accepting vaccination, but would like more information, should be offered online interactive triage to address questions and doubts that they may have about the effectiveness of vaccines, as part of a 'call system'. Those needing face-to-face consultations should be directed via online systems or telephone service to an appointment with an HCW. There should also be an open access drop in consultation service that is provided at easy to reach locations and open at convenient times. Outreach decision aid sessions should also be offered in locations such as community centres, kindergartens, play groups and schools.
4. HCW should be provided with materials and a structured and assessed training programme to help them initiate discussions and answer parents' questions about VE, other issues associated with vaccination, or other preventive measures.

5. Use mass media and digital media to encourage parents and care givers to have a conversation about VE and risk concerns with a HCW; how to access such a consultation.

Cell 9: Attitude of HCWs

Communication tactics:

1. All relevant HCWs should be provided with summary snapshots of what is known about the attitudes and beliefs of people who are being encouraged to take up vaccines including the views and beliefs of UVG's. This information should include details of major issues that research has shown that these groups may want to discuss.
2. All HCW should be provided with scripts, questions and phrases that may help them initiate and guide discussions about vaccination, thus enabling people to make informed decisions about uptake or rejection of the vaccine.
3. Provide (ideally before an outbreak) staff training and development on insights about population views and beliefs and how to communicate about these using tested scripts, phrases and questions.
4. Provide staff that will be having conversations about vaccination with a simple way to log the audience segment (Record the segment that the person falls into for later review of uptake and use of the service to assist future planning and provision), any issues raised and the outcome of the discussion. This material should be used to track concerns that may need further explanation/exploration, and the impact of such conversations on the target segments responding.
5. Use digital and targeted mass media such as professional journals and magazines to set out guidance and testimonials of the importance of developing and sustaining trust by HCW. Use trusted spokespersons that the HCW can relate to and like. Ask for feedback from HCW about their experience of, and good practice in, initiating and having conversations with parents/ care-givers about severity, safety and effectiveness of vaccines and other public health measures.

Cell 10: Trust in government and health authorities

Communication tactics:

1. Use trusted spokespeople and members of communities to promote the uptake of vaccines and the public health measures advocated, via mass and digital media. Use a mix of government and non-government spokespeople to endorse public health advice. Use other third party advocates to build trust in the systems such as doctors, mothers, fathers and trustworthy personalities.
2. Use digital and mass media to stress the importance of the choice that needs to be made. Frame the messages in terms of risk that people can understand and relate to, and frame the message about the safety and effectiveness of the vaccine(s) in unambiguous terms that can be understood by UVG's and other sections of society

3. Use third party advocates such as community organisations and professional associations to endorse the action that government is advocating /co-ordinating.
4. Provide proactive continuous briefing for mass and digital media owners and providers of content about relevant aspects of a major outbreak / incident (e.g. a pandemic), including all relevant data, risk assessments, and assessments of issues related to vaccine safety and effectiveness.
5. Encourage debates on TV, radio and among online communities about the key factors that need to be considered when making decisions about vaccination. As part of this process develop a list of myths and factual untruths that are identified. Develop an easy to understand response to each of these myths and untruths and make sure that this is made widely available to media content providers, editors and journalists, as well as government and supporter organisations such as professional associations, other parts of government, key and trusted NGOs.

12.3 Performance objective: Get the vaccination

Cell 11: Perceived severity of the disease and its potential complications

Communication tactics:

1. At clinics and other vaccination centres (i.e. at 'point of decision'), posters, audio visual material and printed material should be used to encourage and praise uptake of vaccines as the wise choice. Mass media, digital media and health and social care sectors - working with the education sector - should deliver information campaigns about how, where and when to get vaccines. Information should emphasize the ease and low cost associated with uptake.
2. To ensure that UVG's have a high perceived severity of the disease and potential disease-related complications, mass and digital media should be used to inform groups about the number of people suffering due to non-vaccination. This information should be illustrated via both statistical updates but also by personalised stories (providing there is consent) about individuals and the impact on them and their families. Coordination with mass and digital media providers can help to spread these personal interest stories about the need for vaccination.
3. Incentives and conditional cash payments should be considered to promote uptake. Penalties and disincentives should also be considered. Incentives and penalties will need to be researched to ensure that they are perceived as being, fair, significant and proportional if maximum compliance is to be achieved.
4. Vaccine provision and access should be set up in such a way that it is easy and convenient for UVGs. Times, locations and style of service delivery should be considered to facilitate and promote access.
5. Branding and promotions of vaccine and any other public health measure/ service should be considered from the UVG perspective and the perspective of the general population. Branding and promotions should be guided by target group preferences (assessed locally).

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Cell 12: Vaccine safety

Communication tactics:

1. At clinics and other vaccination centres (i.e. at 'point of decision'), posters, audio visual material and printed material should be used to encourage and praise uptake of vaccines as the wise choice. Provide targeted information to UVGs about the safety of vaccines and any other recommended public health interventions. Stress loss of protection if no action is taken and positive and peace of mind as well as safety and protection that will be gained if action is taken. Use direct mail and ambient promotions such as posters in places used by the target group.
2. Develop easy to understand printed material (language, literacy etc.) and distribute this via direct mail to all UVGs and other identified vulnerable sections of the community about how to get vaccines, where to get them, how to contact the providers and how many shots they need.
3. Undertake face-to-face outreach work with UVGs and the general population by public health staff and frontline clinical staff using developed and insight informed scripts about the safety of vaccines and all other recommended public health actions. Offer one-to-one discussions with any member of the targeted groups that would like to discuss safety concerns.
4. Do not run mass media general population campaigns focused on safety or side effects as this may have negative impacts on perception of safety due to attempts to provide so called 'balanced' reporting by journalists and other media content providers. As an alternative provide an instant rebuttal media service that challenges any mass media stories or features about safety that are not factually accurate.
5. Provide to all mass media channels and representatives of UVGs regular safety and preparedness bulletins before pandemic events. This on-going briefing work should aim to raise trust and confidence in public health systems readiness to act in the case of a new event. Also, provide an online and face to face Q&A service focused on safety and side-effect issues for concerned members of the public.

Cell 13: Vaccine effectiveness

Communication tactics:

1. At clinics and other centres where vaccination decisions are being made, posters, audio-visual material and printed material should be used to encourage and praise uptake of vaccines as the wise choice. Also provide targeted information to UVGs about the effectiveness of vaccines and any other recommended public health interventions. Stress loss of protection if no action is taken and positive and peace of mind as well as safety and protection that will be gained if action is taken. Use direct mail and ambient promotions such as posters in places used by the target group.
2. Develop easy to understand printed material (language, literacy etcetera) and distribute this via direct mail to all UVGs and other identified vulnerable sections of

the community about how to get vaccines, where to get them, how to contact the providers and how many shots they need.

3. Undertake face-to-face outreach work with UVG and the general population by public health staff and frontline clinical staff using developed and insight informed scripts about the effectiveness of the vaccine and all other recommended public health actions. Offer one-to-one discussions with any member of the targeted groups that would like to discuss VE.
4. Run mass media general population campaigns focused on the effectiveness of vaccines and the protection they provide. Also use personal testimonials from parents and other care providers who have used the vaccination service. Use people to give testimonials that are liked and trusted by the target groups.
5. Provide to all mass media channels and representatives of UVG regular effectiveness and preparedness bulletins before and during pandemic events. Also provide an online and face to face Q&A service focused on VE issues for concerned members of the public.

Cell 14: Attitude of HCWs

Communication tactics:

1. Provide HCW with tested and insight informed scripts to guide what they say about VE and safety to people in the process of receiving, or contemplating getting vaccines. HCWs should be provided with opportunities and training to experiment and use these scripts in safe role play situations and receive feedback on their delivery.
2. HCWs should be provided with their own direct professional advisory service to assist them with dealing with requests for information at the point of vaccination about vaccine safety, effectiveness and possible side effects. This service should be available online and via telephone support ideally before during and after an event.
3. HCW should be provided with written material such as factsheets and guides to give to parents and other care providers **post**-vaccination to reinforce advice given at the point of vaccination. This material should be designed for different groups but should be universally easy to understand (literacy), and give clear advice about what to do if any complications associated with the vaccine are perceived by the parent or care giver.
4. As part of the routine vaccination programme, HCWs should be encouraged to proactively reach out into the community and specifically with UVGs to assist them and answer any concerns they have. A programme of proactive health promotion outreach should be developed as part of an overall immunisation programme communications strategy.
5. Research should be carried out with HCWs to develop insight into their attitudes and beliefs. If necessary, professional development sessions should be developed to fill any gaps they have in their knowledge about vaccine safety and effectiveness, and the best evidence about communication and behaviour change to promote vaccine uptake.

Cell 15: Trust in government and health authorities

Communication tactics:

1. IPH's and other relevant organisations should publish data in easy to understand formats using graphical illustrations details of coverage and uptake by groups of the population together with risk assessments associated with any lack of uptake. This material should be made available online and in the form of briefing papers sent to all politicians, media sources and relevant stakeholder communities and professional associations.
2. IPHs and other relevant organisations should develop and promote via traditional and digital media ways for the public, professionals and communities to feedback questions, views and potential ideas about how to promote and maintain uptake and compliance with recommended actions. These views and ideas should be shared and publicised in vaccine information and promotion materials or information bulletins (with contributors / sources of 'good practice' ideas acknowledged). At clinics and other places of decision-making, posters, audio-visual material and printed material should be used to praise uptake of vaccines as the wise choice and alert people to other public health services provided by the government, the positive impact of the total public health service, and peoples' key role in helping the government deliver positive public health ('public health is everybody's business').
3. Mass media and 'point of decision' sites such as family doctor surgeries, community clinics, CWCs and hospitals should display printed material and other forms of audio-visual material to let people know how they can make suggestions for improving service delivery, via online or telecommunications, a 'suggestion box' in the clinic, and/or via face-to-face feedback services.
4. Governments should run (and publicise the fact that they are running) user feedback forums on a regular basis, prior to, during and after an outbreak, about how to best communicate with and inform members of the public and UVGs. The results of these feedback sessions should be publicised using traditional and digital media, setting out how this feedback will be translated to changes in communication tactics and service delivery.

12.4 Performance objective: Take preventive measures

Cell 16: Perceived severity of the disease and its possible complications

Communication tactics

1. The disease severity and risk of being unvaccinated should be publicised using traditional and digital media together with prevention measures that can be taken easily. The use of easy to remember phrases and graphic representations of suggested measures should be used on all material. All media or other messages should be consistent, and be perceived as being so by target audiences.

2. Focusing on severity and risk, develop and promote a limited and specific set of actions on the basis of the best available evidence that such actions protect people / reduce risk of acquiring disease / attenuate disease if infection is acquired/ reduce risk of onward transmission. Actions should be achievable and specific such as: cough hygiene: use a paper handkerchief to catch sneezes then bin it (i.e. the 'catch it, bin it, kill it' message), hand hygiene: wash hands with soap and water frequently, or relevant exclusions: e.g. avoid busy areas or exclude from work/ school/ kindergarten.
3. Develop communications strategies focused on reducing risk of acquiring infection or transmitting infection onwards, with providers of preventive material such as soap, paper tissues and manufacturers and distributors of personal protective equipment (PPE) such as face-masks, to promote the uptake of these and other relevant products where appropriate. Consider government endorsements for relevant effective products/ range of products (e.g. a list of products/ producers who meet the required standard).
4. Create and distribute information materials geared towards the media, such as press briefings, fact sheets, FAQs, and news releases (proactive and reactive). This should be part of an overall plan that includes a timeline for releasing materials regularly.
5. Use research regarding knowledge, attitudes and beliefs to design story angles for the media about disease severity and the risks of being unvaccinated (in a risk/ benefit framework), including for television, specialized publications, radio and magazines as well as traditional newspapers, online publications, blogs and social networks.

Cell 17: Vaccine safety

Communication tactics:

1. The safety and ease of infection prevention / onward transmission prevention measures should be promoted using traditional and digital media in parallel. The use of easy to remember phrases and graphic representations of the recommended actions should be used and be consistent on all materials/ via all channels. It should also be perceived as being so by target audiences.
2. Focus on preventive actions that do not conflict with their UVGs existing belief sets. Suggest and promote a limited and specific set of actions on the basis of evidence that such actions protect people / reduce risk. Actions should be achievable and specific such as: cough hygiene: use a paper handkerchief to catch sneezes then bin it; hand hygiene: wash hands with soap & water frequently; or relevant exclusions: e.g. avoid crowded areas, relevant exclusions from work/ school/ kindergarten.
3. Develop communications strategies focused on reducing risk of acquiring infection or transmitting infection onwards, with providers of preventive material such as soap, paper tissues and manufacturers and distributors of personal protective equipment (PPE) such as face-masks, to promote the uptake of these and other relevant products, where appropriate. Consider government endorsements for relevant effective products/ range of products (e.g. a list of products/ producers who meet the required standard).

4. Create and distribute prevention information materials geared toward the media, such as press briefings, fact sheets, FAQs, and news releases (proactive & reactive). This should be part of an overall plan that includes a timeline for releasing materials regularly.
5. Use research regarding knowledge, attitudes and beliefs to design story angles for the media about the safety of preventive action (such as the safety profile of a vaccine), including for television, specialized publications, radio and magazines as well as traditional newspapers, online publications, blogs and social networks.

Cell 18: Vaccine effectiveness

Communication tactics:

1. The effectiveness of the vaccine should be promoted using traditional and digital media together with prevention measures that can be taken easily; but this should not lead to the exclusion of promoting the uptake of vaccines. Preventive actions should be promoted alongside vaccination as a total package of preventive actions.
2. The general public, including UVGs should be encouraged to view preventive action/ prevention measures as a key part of a total protection and risk reduction programme. IPHs and other relevant health and community organisations should use mass and digital media together with direct mail at point of decision locations such as clinics and schools to promote a total protection/prevention message.
3. Develop communications strategies - focused on the effectiveness of vaccines as part of a total protection/ prevention programme - with relevant stakeholders capable of spreading the message such as schools, workplace occupational health services, community centres and the entertainment sector.
4. Create and distribute information materials geared toward the media about the effectiveness of vaccines in parallel with other preventive actions. Consider approaches such as press briefings, fact sheets, FAQs, and news releases (proactive & reactive). This should be part of an overall plan that includes a timeline for releasing materials regularly.
5. Use research regarding knowledge, attitudes and beliefs of UVGs to design story angles about the effectiveness of vaccines for the media, including for television, specialized publications, radio and magazines as well as traditional newspapers, online publications, blogs and social networks.

Cell 19: Attitude of HCWs

Communication tactics:

1. All HCWs should be provided with summary snapshots of what is known about the attitudes and beliefs among the general population and among UVGs in relation to taking recommended preventive measures, including vaccination.
2. All HCWs should be provided with scripts, questions and phrases that may help people make informed decisions about uptake or rejection of the recommended

preventive actions, including vaccination. These scripts should cover both starting conversations about vaccination/ other preventive measures and having them.

3. Provide to relevant healthcare staff, regular staff training and development on insights about population views and beliefs in relation to recommended prevention measures including vaccination, and how to discuss and communicate about these using tested scripts, phrases and questions.
4. Provide HCWs who will be having conversations (in relation to prevention measures such as vaccination) with UVGs among others, a simple way to log and report the audience segment, document the issues raised, and the outcome of the discussion. This material can be used to track concerns and issues that may need further explanation/exploration and the impact of those concerns on the uptake of recommended preventive measures.
5. Use digital and targeted mass media such as professional journals and magazines to set out guidance about what prevention measures to recommend, the evidence of effectiveness of those measures (where this is known) and how to communicate these recommendations.

Cell 20: Trust in government and health authorities

Communication tactics:

1. Before (e.g. at start of 'flu season) and (timely) during an outbreak have a credible public health spokesperson provide information to the public about recommended preventive actions which have been shown to reduce risk of acquiring infection. Respond to initial questions from the public openly and rapidly. Credibility hinges on early reaction and response to an outbreak.
2. Establish on-going dialogue with key opinion formers and leaders of UVGs. Develop an on-going relationship plan for each group focused on promoting the uptake of recommended public health preventive actions. Arrange regular briefings for opinion formers and leaders of UVGs (prior to), during and after any significant outbreak/ incident. Provide - via the WWW - a transparent account of issues such as vaccine development and procurement, vaccine safety tests, potential vaccine side effects and assessments of the level of protection provided by the vaccine (in a risk/ benefit framework).
3. Use mass media and digital media to present testimonials from trusted sources such as doctors, Public Health leaders and, if possible, members of UVGs to promote trust in the preventive public health measures being advocated.
4. Use political spokespersons with the highest trust ratings possible to act as advocates for preventive actions.
5. Use trusted spokespeople and testimonials from members of UVGs to endorse compliance with recommended public health prevention measures and to explain why those measures are compatible with the respective belief systems. Promote these endorsements through specialist media channels such as via relevant publications, websites and other forms of digital media, and via face-to-face gatherings such as community meetings and religious events.

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13. Conclusion

This project presents tools to increase the ability of governments and health authorities to effectively communicate the need for large-scale preventive measures such as vaccination during outbreaks, and to increase the acceptance of preventive measures among the general population and specific UVGs.

It has been a collaborative process, involving multi-disciplinary stakeholders from social science, anthropology, communications and public health, from across the EU. This project has been designed to link with other relevant WPs included in the EU project "Effective Communication in Outbreak Management: development of an evidence-based tool for Europe" but also using information from other WHO or ECDC projects.

We identified a number of UVGs in three selected European countries (Portugal, the Netherlands and Romania), and described those in the first part of this report. Thereafter, we describe the factors that determine the decisions they make about vaccinations included in the NIP. The determinants were always studied in between outbreaks, we did not find studies on determinants during pandemics or outbreaks. Among the identified UVGs there are a variety of beliefs about, and objections to vaccination. Some ideas are common across several groups. In addition, the UVGs we reviewed also have determinants in common with the general population with regard to vaccination in general unrelated to outbreaks [1, 2, 8, 9, 94]. Furthermore, during the influenza A(H1N1) pandemic in the general population also the same determinants were found in various countries [10, 11, 95].

Describing communication strategies in Part II on the determinants most easily influenced or amenable to change seemed to be more relevant than describing a separate communication strategy for each UVG. However, when communication programmes are being developed and implemented locally (or nationally), the specificity and the tendency of each UVG needs to be taken into account in framing the tactics.

In addition, HCWs are the first interlocutor for health concerns for members of these groups thus it is very important to include them in the communication process. It seems impossible to motivate UVGs without the support and the motivation of HCWs. Therefore, we also need to consider how to convince HCWs of the benefits of vaccination. Different tools, guide and documents are available on ECDC and WHO-Europe websites to assist health professionals in their day-to-day work as it relates to immunization (Appendix 14.4).

Via the DPOM Tool, a number of CBI tactics for UVGs are suggested, that can be used by health professionals and agencies throughout Europe, in the framework of their own NIP and their own UVGs and during and in between outbreaks. It must be emphasised that the communication approaches set out here are not presented as a total and complete set of

interventions; rather they are illustrative of several communications components of a fuller programme.
Communicating with UVGs in order to fulfil their information needs, to improve their trust in government and the IPH and to help them to make a well-considered and informed decision about vaccination is crucial – for routine vaccination programmes, and particularly in the case of a major outbreak, in order to improve herd immunity, reduce the risk of acquiring infection, particularly among vulnerable individuals in those communities, and the risk of the potential consequences of severe disease; thus impacting on morbidity and the mortality.

However, the communication has to start as soon as possible. To be effective, we do not have the luxury to wait for the next outbreak to initiate communication, but we need to embed regular (proactive) communication with these groups to build relationships and trust. The communication tactics suggested in this report should be implemented soon in order to start effective communication with UVGs and to have impact on the uptake of routine vaccination, to the benefit of all.

14. Appendixes

14.1 Two literature reviews (Part I)

14.1.1. Planned approach

We performed two literature reviews: the first aimed at identifying UVGs in Europe and the second focused on beliefs, ideologies, attitudes and objections toward vaccination of the identified UVGs. In this report we describe the UVGs and their beliefs toward vaccination in the three selected countries (i.e. Portugal, Romania and the Netherlands). In the manuscript "Under-vaccinated groups in Europe and factors regarding their acceptance of vaccination: two literature reviews" (to be submitted) we describe the UVGs and their beliefs toward vaccination in **all** European countries.
These two literature reviews followed the steps described in detail below. The first step of the review was to frame the questions for the review. In the second step, we identified relevant literature by using different search strategies.

14.1.2. Step 1 - Review questions

First systematic review:
Who are the UVGs in Europe (as defined in chapter 1.3)?

Second systematic review:
What are the arguments, beliefs, ideologies, attitudes and objections concerning vaccination of UVGs we identified?

14.1.3. Step 2 – Identifying relevant studies to be included in the review

Search strategy:
For both reviews, we defined a list of search terms and a specific search term combination, including all European countries, based on MeSH (Medical Subject headings) and 'free text' (i.e. title and/or abstract) terms. Search strategies were designed in close collaboration with RIVM library staff. The list could be adapted according to the key words found in the full-articles. Three electronic databases - MEDLINE (PubMed), EMBASE, and PsycINFO were used to search for pertinent peer-reviewed articles.

In the first literature search, in order to identify UVGs in Europe, we looked for articles that focused on outbreaks of VPDs and/or of low vaccination coverage among groups / communities as defined in Chapter 1.3, i.e. organised as a community who share the same ideological way of life and/or who share the same beliefs and ideological motives concerning vaccination.

Once we identified UVGs, we performed a second literature search based on names of these groups and on a search term combination; selecting articles that focused on beliefs, attitudes, and perceptions of the identified groups towards vaccination.

Selection of articles
A snowball strategy was used to identify relevant peer-reviewed articles. Relevant citations from articles indexed in these two search engines were also reviewed. In addition, if relevant findings about beliefs of UVGs were found in the full-text articles from the first literature review, we selected these articles for the second search.
Two reviewers (NF LM) selected independently the relevant articles according to the inclusion criteria defined above. Firstly, the selection was based on title and abstract for papers identified in Medline and only on title for papers identified in the two other databases. The final selection was done on full-paper. In case of discrepancy, a third reviewer (JS) would be asked to review articles.

Inclusion and exclusion criteria for the database review
- Only English language papers were included
- Only peer-reviewed articles
Papers published between 1950 up until May 2013 were included; we decided to start in 1950 because many NIP in European countries began in the 1950s.
Selection of the relevant studies to be included in the review

Support
Performing the review was supported by RIVM library staff (search strategy, carrying out the search, deduplication of identified papers, requesting manuscripts, etcetera).

For this report we also accessed the grey literature, including: published and unpublished reports relating to UVGs from Public Health Institutes (e.g. outbreak reports), and unpublished (as yet) in-depth studies by researchers from the respective countries who were collaborating on the project. We also accessed websites of particular UVGs, where these were available.

14.2 National immunisation programmes and vaccination coverage

14.2.1. The Netherlands

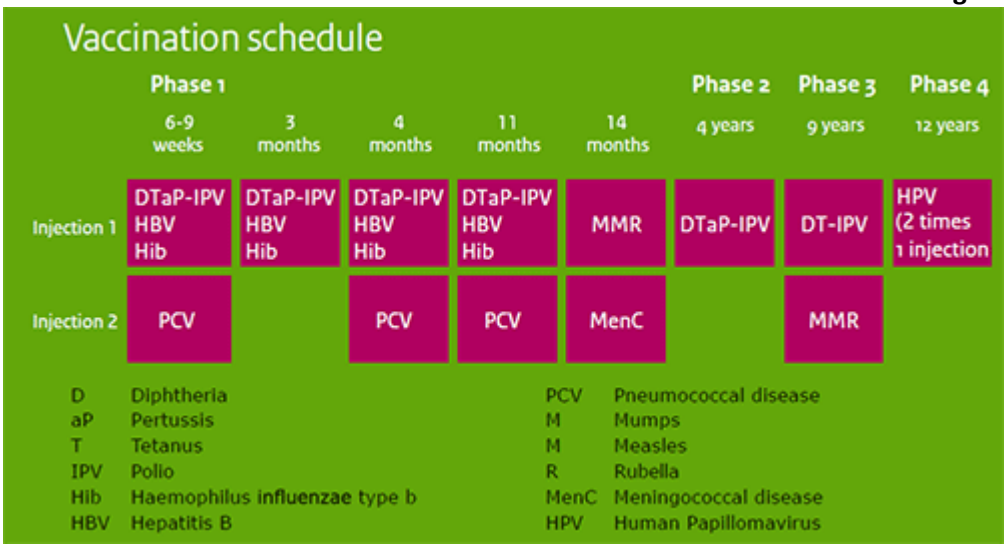
National immunisation programme[19]
Nowadays, vaccinations against 12 infectious diseases are included in the NIP (diphtheria, poliomyelitis, pertussis, tetanus, *Haemophilus influenzae* type b disease, meningococcal group C disease, measles, mumps, rubella, hepatitis B, pneumococcal disease, and cervical cancer caused by human papilloma virus). In the Netherlands, all children are offered vaccination free of charge and on a voluntary basis via local child health clinics (CHC) or via municipal health authorities as part of a NIP, as per the schedule in Table 1 below. During the standard home visit for every new-born, the CHC nurse may provide the parents with vaccination information and registers whether the child will participate in the NIP or not. If

[19] Immunization coverage National Immunization Programme in the Netherlands: Year of report 2011 http://www.rivm.nl/bibliotheek/rapporten/210021014.pdf

the parents are unsure, the topic is addressed by the CHC doctor during the first consultation at the CHC. General practitioners (GPs) or family physicians are seldom involved in the NIP. Other medical care, however, primarily involves GPs.

The GPs conduct the Influenza Immunisation Programme, focused on adults and children with a medical indication such as chronic heart or lung disease. Like the NIP this Influenza Immunisation Programme is offered free of charge.

Table 4: Current vaccination schedule of the Dutch National Immunisation Programme



The NIP is implemented by the Public Health Institute (RIVM). The RIVM is also registering the vaccinations and evaluates the programme and the vaccination coverage. Adverse events are registered by the Netherlands Pharmacovigilance Centre Lareb.

Vaccination coverage

In the Netherlands, all vaccinations, administered within the framework of the NIP are registered in a central electronic (web-based) database on the individual level (Præventis). In 2015, the average participation for the various vaccinations (except for HPV with 61%) included in the NIP is between 92% and 99%. The participation among schoolchildren for MMR was similar as for DT-IPV (93%), but is still below the WHO target of 95%.

Surveillance

For all target diseases of the NIP, the tools: pathogen surveillance, clinical surveillance, surveillance of adverse events of vaccines, surveillance of the vaccination coverage (including monitoring acceptance of vaccination) and serosurveillance. From 2008, 42 notifiable infectious diseases (including VPDs) have to be reported by physicians, laboratories and heads of institutions to Public Health Services. Adverse events following vaccination are also investigated passively and actively. An enhanced spontaneous reporting system for AEFI is combined with a telephone service for consultation and advice on schedules,

contraindications, precautions, adverse events (AE) and other vaccination related problems. As from 1st January 2011 the Netherlands Pharmacovigilance Centre (Lareb) has guided the enhanced reporting system.

14.2.2. Portugal

National immunisation programme

The Portuguese NIP exists since 1965 and is universal, free of charge, not compulsory and accessible to everybody in the country. Since 2012, vaccination against 12 infectious diseases is included in the NIP (diphtheria, polio, pertussis, tetanus, *Haemophilus influenzae* type b disease, measles, mumps, rubella, hepatitis B, Meningococcal C disease, tuberculosis and cervical cancer caused by human papilloma virus). Vaccines are administered by nurses at the local healthcare centres and hospitals (mostly public services, occasionally school-based), according to the schedule in Table 2 below:

Table 5: Vaccination schedule of the Portuguese National Immunisation Programme, 2012[20]

	Birth	Months					Years			
		2	4	6	12	18	5-6	10	13	18
tuberculosis	BCG									
diphtheria		D	D	D		D	D	d		d[1]
tetanus		TT	TT	TT		TT	TT	TT		TT[1]
pertussis		acP	acP	acP		acP	acP			
poliomyelitis		IPV	IPV	IPV			IPV			
Haemophilus influenzae type b infection		Hib	Hib	Hib		Hib				
hepatitis B	HepB	HepB		HepB						
meningococcal Disease					MCVC					
measles					MEAS		MEAS			
mumps					MUMPS		MUMPS			
rubella					RUBE		RUBE			
human papillomavirus infection									HPV[2]	

General recommendation for Portugal [-] Specific recommendation for Portugal Catch-up for Portugal

Footnotes
1: Td booster every 10 years for adults
2: Three doses. Females only.

More information available at: http://www.portaldasaude.pt/portal/conteudos/informacoes+uteis/vacinacao/default.htm

[20] http://vaccine-schedule.ecdc.europa.eu/Pages/Scheduler.aspx

The Directorate-General of Health (DGS) (directly linked with the MoH) coordinates the NIP through (http://venice.cineca.org/documents/portugal_ip.pdf):

- Hosting and leading the Vaccination Technical Committee
- Releasing national vaccination guidelines
- Technical liaison with the pharmaceutical industry
- Monitoring vaccination coverage at national and regional levels
- National mandatory surveillance of VPDs
- Cooperation with other national institutions

The National Institute for Pharmacy and Medicines is in charge of authorising the marketing of the vaccines (like other medicines), controlling the lot quality and monitoring AEFI (included in the Adverse Drug Reactions Monitoring System).

Vaccination coverage

A national computerised vaccination registry system was gradually implemented in 2000 (http://venice.cineca.org/documents/portugal_ip.pdf), which records all individual vaccine inoculations; thus allowing management of vaccine stock nationally and estimation of vaccine coverage annually by birth cohort. Vaccine coverage is high - about 95% - and is relatively homogenous across the Health sub regions. In 2011, the vaccination coverage was 97% for BCG and HepB among the 2011 birth cohort and 96% for MMR among children of 24 months.

Surveillance

Portugal has a national mandatory surveillance of all VPDs in place (http://venice.cineca.org/documents/portugal_ip.pdf).

14.2.3. Romania

National immunisation programme

In 2012, vaccination against 10 infectious diseases is included in the NIP (diphtheria, poliomyelitis, pertussis, tetanus, *Haemophilus influenzae* type b disease, measles, mumps, rubella, hepatitis B, and tuberculosis).

In Romania, all children are offered vaccination free of charge and on a voluntary basis via hospitals (at birth), and GP clinics as part of a NIP, as per the schedule in Table 3 below.

Table 6: Vaccination schedule of the Romanian National Immunisation Programme, 2012[21]

	Birth	Months				Years				
		2	4	6	12	4	6	7	8	14
tuberculosis	BCG[1]									
diphtheria		D	D	D	D	D	D[2]			d[3]
tetanus		TT	TT	TT	TT	TT	TT[2]			TT[3]
pertussis		acP	acP	acP	acP	acP	acP[2]			
poliomyelitis		IPV	IPV	IPV	IPV		IPV[2]	IPV[4]		
Haemophilus influenzae type b infection		Hib	Hib	Hib	Hib					
hepatitis B	HepB[5]	HepB		HepB						
measles					MEAS			MEAS[3]		
mumps					MUMPS			MUMPS[3]		
rubella					RUBE			RUBE[3]		

General recommendation for Romania [-] Specific recommendation for Romania Catch-up for Romania

Footnotes
1: Administration during the 2-7 days after delivery
2: DTacP-IPV at 6 years to begin in 2015
3: school-based programme
4: ongoing until 2014, including
5: within 24 hours after birth

More information available at: http://www.insp.gov.ro/cnscbt/index.php?option=com_docman&Itemid=3

Vaccination coverage

All vaccinations, administered within the framework of the NIP are registered in a central electronic (web-based) database. The first analysis of national register data has not yet been published due to the relatively recent implementation.

The results of a survey from GP's registries, done in August 2011, for children aged 24 months, showed an average uptake for some vaccinations (BCG, HepB3) included in the NIP, considerably over 95%. The vaccination coverage for DTaP-IPV was 93.4% and 94.7% for MMR1.

Surveillance

For all target diseases of the NIP, the impact of the programme is monitored through mortality, morbidity and laboratory data related to the specific diseases. Since 2009, all diseases targeted by the NIP are reported through a national computerized registry.

AEFI are included in the national surveillance system. The notification is mandatory and the information is sent through national registry and specific forms. In 2011, 46 confirmed AEFI were reported [NIP RO, 2011-2012].

[21] http://vaccine-schedule.ecdc.europa.eu/Pages/Scheduler.aspx

ECOM

14.3 Recommendations from WP3 about behavioural analysis (Part II)

Citizen[22] Focused Solutions

If the outcome of pandemic communication and behavioural influencing strategies is to achieve a positive, accurate and trusted understanding and experience of government policies related to pandemic management and compliance with recommended actions the approach must be to move away from a top down one way communication dominated model. We need to move towards a model that is based on customer needs, dialogue and feedback with people we seek to influence and an approach that is responsive to demands and changing circumstances. We also need an approach that is focused more on impact and outcome measurement in terms of actual behaviour.

Public Permission Matters

The more powerful and subtle behavioural change approaches are, the more they may provoke public and political concern. Behavioural approaches that embody a line of thinking that moves from the idea of an autonomous individual making rational decisions to a decision-maker, much of whose behaviour is automatic and influenced by their choice environment raises the question of who decides on and who can influence this choice environment? One of the key challenges that will face public health planners who seek to use no- rational approaches that seek to build relationship influence is how the permission to use these approaches will be given and legitimised in order that a backlash of public opinion does not result in accusations of trickery and manipulation.

The advances in understanding and methodological development in the field of systematic health programmes and behaviour change planning need to be better integrated into pandemic CBI programme management

The development of more systematic approach to health behaviour change [23] and a growing body of research[24] that goes beyond communication theory [25] has been developing over recent years[26] [27]. Intervention forms such as social marketing[28], co-creation[29] and community engagement[30] are examples of these new forms of social policy delivery. This development

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[22] We use the term 'citizen' to indicate members of the public, the exact word to be used will need to be considered in the light of debate resolution in relation to the issues raised in section two of this paper.

[23] Michie S, M van Stralen M ,West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci. 2011; 6: 42. Published online 2011.23.

[24] CDC The Community Guide. What works to promote health? http://www.thecommunityguide.org/worksite/supportingmaterials/IES-AHRFAlone.html. CDC Atlanta.

[25] McQuaid D Mass Communication 5th edition Theory Sage 2009

[26] National Institute for Health and Clinical Excellence (2007) *Behaviour change at population, community and individual levels. Reference Guide.* London: NICE

[27] It's our health. National Consumer Council. 2006

[28] French J. Blair- Stevens C. Merritt R. McVey D. Social Marketing and Public health, theory and practice. Oxford University Press 2010

[29] Cottam, H. Leadbeater, C. Red Paper No1 health: Co-creating Services. The Design Council. London. 2004.

[30] *Hills D. 2004 Evaluation of community – level interventions for health improvement: a review of experience in the UK. . HDA. London.*

along with more general improvement in social policy implementation[31] planning[32] has resulted in a growing consensus about how to go about establishing, delivering and evaluating more successful behavioural programmes in the social sector. This understanding should be used to shape intervention programmes.

Evidence driven but not evidence restricted

It is probable that governments and public health agencies will always use some forms and types of intervention that are not fully supported by strong evidence. Interventions such as social advertising should not be dismissed as ineffective, rather government and public health organisations should ensure that they apply best practice when developing these forms of intervention. A culture of systematic planning and evaluation should be encouraged to enable transparent reporting on the impact and efficiency of all programmes. This will help with developing the evidence base[33] for communication and behaviour change interventions in the field of pandemic management. The use of pilot testing should also feature in all programmes.

Cultural and organisational issues, the status of communication and marketing

Behavioural influence and communications often exists as a bolted on adjunct (all be it a vital one) to the influence of medical and epidemiological understanding in the policy development and strategy development process. Communication and those responsible for influencing behaviour in relevant organisations often operates in an environment where messages and policies are developed prior to and independently from a marketing and communications strategy. This often leads to a producer-led selling approach, i.e. a focus on broadcasting evidence based messages about risk reduction and communication focused on compliance with medical opinion. A significant cultural and technical shift is required within governments and specialist responsible agencies to a more customer-led marketing approach, and a fully integrated partnership between marketing and communications professionals and policy and delivery professionals.

Capacity and Capability

Marketing practitioners in many governments across Europe have excellent technical skills, but there are many countries where this capacity is not so well developed. There is a need to continue to build and sustain a high-level of professional capacity and the marketing and communication professional community will need to have the skill-set that will enable them to engage in policy development as well as programme delivery and evaluation if marketing and communications is to be more strategically engaged in pandemic preparedness policy formulation. The implications of adopting such an approach could include countries undertaking a marketing and communications capacity and skills audit and the development of an assistance programme to develop training courses and mechanisms for sharing of best

[31] Good Government. Public Administration Select Committee. (2009) House of Commons London: The Stationery Office Ltd

[32] Australian Public Service Commission (2007) *Changing Behaviour a public policy perspective. Australian Public service Commission.* Barton, ACT: Australian Government Publishers Ltd. 2009.

[33] Applying behavioural insight to health. Cabinet Office Behavioural Insight Team London 2011

practice and skills and other competences for example, influencing policy makers, stakeholder management and leadership skills.

Budgets and other assets
All EU countries hold and deploy their own resources alongside neighbouring countries and also the efforts of international regional organisations such as the ECDC, CDC, and the WHO. Annual budget allocations can fuel short-termism. Budgets are also often allocated as a single entity rather than being divided between development, piloting, execution and evaluation. Ideally budgets should be allocated to cover the complete timescale for the planned activity and should be justified not only in terms of achieving quantified objectives and in terms of programme delivery, but also how the activity will contribute to the overall strategy as a whole. The possibility of cross boarder alignment of marketing and communication resources should be investigated to ensure that budget management is optimal.

Silo research and evaluation
There are no current reliable estimates for how much is spent on marketing and communications research in the field of pandemic preparedness and management across Europe. However, it is reasonable to conclude given the size and importance of the issue to governments that the aggregate figure is significant. Most of this research is commissioned for individual agency programmes rather than for the European common good. The implications of adopting such an approach would include:

- Closer liaison and co-ordination with medical, epidemiological, social and marketing and communications research
- Initiate more centrally/ joint-funded marketing and communications research projects to minimise overlaps and maximise strategic joined up opportunities.
- Use ‘upstream’ horizon scanning and developmental research to pro-actively set the strategic marketing and communications agenda across European countries and specialist agencies.
- Develop standardised procedures for evaluative research to demonstrate the effect of pandemic marketing and communications programmes with the public but also inter and internal organisational communications programmes. This research should develop protocols for process measures of campaign efficiency, impact evaluation i.e. short term change such as awareness, as well outcome measures such as behaviour change or compliance.

14.4 Existing technical reports for health professionals and others
Various organisations such as ECDC and WHO provide several documents, guide and technical reports on their website about how to communicate on immunization, determinants of behaviour and behavioural interventions. These can be used for health professionals and others to assist them in their day-to-day work as it relates to immunization. Some of these documents aimed to provide health professionals with information and training, and others are targeted to be shared with patients, to provide them with important information about immunization and vaccine-preventable diseases. Below we list some of the reports per organisation.

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- Conducting health communication activities on MMR vaccination (2010) http://www.ecdc.europa.eu/en/publications/publications/1008_ted_conducting_health_communication_activities_on_mmr_vaccination.pdf "This guide provides an overview of health-communication-related obstacles to measles, mumps and rubella (MMR) vaccination. It provides assistance in the planning and implementation of national communication initiatives on MMR vaccination."

- MacDonald L, Cairns G, Angus K, Stead M. Evidence review: social marketing for the prevention and control of communicable disease (2012) http://ecdc.europa.eu/en/publications/Publications/Social-marketing-prevention-control-of-communicable-disease.pdf To provide an evidence-based summary of social marketing for the prevention and control of communicable disease, with particular reference to the European context.

- ECDC Technical report Communication on Immunisation – building trust (2012) http://ecdc.europa.eu/en/publications/Publications/TER-Immunisation-and-trust.pdf This guide highlights the importance of trust and credibility for public health organisations in order to communicate effectively on immunisation. The document aims at supporting Member States in planning and implementing communication initiatives on vaccination, by presenting an overview of the main issues that public health institutions need to consider in relation to building and maintaining trust.

- Systematic literature review of the evidence for effective national immunisation schedule promotional communications (2012) http://ecdc.europa.eu/en/publications/Publications/Literature-review-national-immunisation-schedule-promotional-communications.pdf
'Immunisation hesitancy' has negatively impacted population uptake of routine immunisation. A substantial body of evaluated communication activity promoting nationally indicated routine immunisation has been published. This systematic review of the evidence aims to: collate and map the types of promotional communication that have been used; assess the quality of the evaluative research reporting on these promotional communications; and assess the applicability of this evidence to immunisation policy, strategy and practice priorities. The analysis and findings are intended to provide a current status report on the evidence, and evidence gaps for good practice in national immunisation promotional communications, thus supporting countries in their communication activities for the prevention and control of communicable diseases.

- A literature review on effective risk communication for the prevention and control of communicable diseases in Europe (2013). http://ecdc.europa.eu/en/publications/Publications/risk-communication-literary-review-jan-2013.pdf

- Systematic literature review to examine the evidence for the effectiveness of interventions that use theories and models of behaviour change: towards the prevention and control of communicable diseases. Insights into health communication (2013) http://ecdc.europa.eu/en/publications/Publications/health-communication-behaviour-change-literature-review.pdf

- Let's talk about protection (2013) On the website of ECDC, different documents are provided (practical peer-reviewed advice, evidence-based guidance and handy tools) to help healthcare professionals who are involved in vaccination to communicate effectively with parents and unprotected and under-protected populations. http://ecdc.europa.eu/en/healthtopics/immunisation/comms-aid/Documents/Vaccine-comms-action-2013.pdf

- Review of outbreaks and barriers to MMR vaccination coverage among hard-to-reach populations in Europe (2013) http://www.ecdc.europa.eu/en/publications/publications/mmr-vaccination-hard-to-reach-population-review-2013.pdf "The overall aim of this project was to report on activities being undertaken to monitor and improve MMR vaccination coverage among hard-to-reach population groups in European countries, building upon previous work done by the VENICE II project on barriers to MMR immunisation. The objective was to describe measles, mumps and rubella outbreaks reported over the last two decades, to provide information on MMR vaccination coverage and to describe known barriers to MMR vaccination among hard-to-reach population groups in EU countries."

- Measles and rubella elimination: communicating the importance of vaccination (2014) http://ecdc.europa.eu/en/publications/Publications/Measles-rubella-elimination-communicating-importance-vaccination.pdf

- Health communication and its role in the prevention and control of communicable diseases in Europe Current evidence, practice and future developments (2014) http://ecdc.europa.eu/en/publications/Publications/health-communication-communicable-disease-europe.pdf

The vaccine confidence project & London School of Hygiene and Tropical Medicine

- The state of vaccine confidence 2015 http://www.vaccineconfidence.org/The-State-of-Vaccine-Confidence-2015.pdf

CDC

CDC The Community Guide. What works to promote health?
http://www.thecommunityguide.org/worksite/supportingmaterials/IES-AHRFAlone.html
See:
http://www.thecommunityguide.org/vaccines/targeted/communityeducation.html

http://www.thecommunityguide.org/vaccines/targeted/healthcaresettings.html
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http://www.thecommunityguide.org/vaccines/universally/IncentiveRewards.html
http://www.thecommunityguide.org/vaccines/universally/clientreminder.html
http://www.thecommunityguide.org/vaccines/universally/healthsysteminterventions.htm
http://www.thecommunityguide.org/vaccines/universally/communityinterventions.html

- Talking with parents about vaccines for children "Suggestions and proven techniques to help health workers foster constructive dialogue with parents about vaccinating their children" http://www.cdc.gov/vaccines/hcp/patient-ed/conversations/downloads/talk-infants-color-office.pdf

- If you choose not to vaccinate your child, understand the risks and responsibilities "Information for parents to help parents who are reluctant to vaccinate understand the implications of such a decision" http://www.sdiz.org/documents/not-vacc-risks-color-office.pdf

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- The Guide to Tailoring Immunization Programmes (TIP) (2013) Increasing coverage of infant and child vaccination in the WHO European Region
  “The "Guide to tailoring immunization programmes (TIP)" aims to provide proven methods and tools to assist national immunization programmes (NIPs) design targeted strategies that increase uptake of infant and childhood vaccinations. The Guide provides tools to identify susceptible populations, determine barriers to vaccination and implement evidence-based interventions.
  The strategies outlined in this Guide may be used at any time to maintain high coverage rates, but may be particularly valuable when pockets of low vaccination coverage or increased susceptibility to VPDs are identified. The Guide may be used independently by Member States or implemented in conjunction with technical support from the WHO Regional Office for Europe” http://www.euro.who.int/en/what-we-do/health-topics/disease-prevention/vaccines-and-immunization/publications/2013/guide-to-tailoring-immunization-programmes

- Vaccine safety events: managing the communications response. (2013) A Guide for MoH, EPI Managers and Health Promotion Units
  http://www.euro.who.int/__data/assets/pdf_file/0007/187171/Vaccine-Safety-Events-managing-the-communications-response.pdf “Managing a country’s immunization programme requires in-depth knowledge of the technical side of vaccination. Increasingly, however, programme managers are also being asked to respond to communications issues caused by real or perceived vaccine-related events (VRE); issues for which they may not have been trained.
  This manual provides practical, informative strategies and tools to help plan and manage a communications response following a VRE in a local community, at a national level, or beyond. By reading this manual, immunization programme managers will learn how to use communications strategies and tools to increase public trust and confidence in vaccines, and to minimize the negative impact of VREs.”

- Report of the SAGE working group on vaccine hesitancy (2014)
  http://www.who.int/immunization/sage/meetings/2014/october/SAGE_working_group_revised_report_vaccine_hesitancy.pdf

USAID

- The Work Place Guide for Managers, Avian influenza Prepared for the USAID Avian Influenza Program by the Academy for Educational Development. http://www.globalhealthcommunication.org/tool_docs/84/Avian_Workplace_Guide.pdf

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