share and move to face nasty bugs

WP5

D5.2 : BEST PRACTICE PLATFORM AND STAKEHOLDER PORTAL REPORT

ASSET Project • Grant Agreement N°612236

ASSET

Action plan on SiS related issues in Epidemics And Total Pandemics

7th RTD framework programme

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D5.2 Report on “BEST PRACTICE PLATFORM AND STAKEHOLDER PORTAL”

Task: 5.2

Leader: IPRI – Other contributors: NCIPD, TIEMS, UMFCD, HU, ZADIG

History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft		IPRI/ALBERTO D’ONOFRIO	
Vf	Final			

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Executive Summary

This report summarizes the multi-level work that has been conducted for the Task 5.2.

The original Description of Work of this Task had to be redesigned under the light of the preliminary work that had been done for the WP1 and WP2 and of the whole previous work of ASSET. Substantial work and discussions among ASSET partners led to the redefining of the description of work for Task 5.2. This implied a partial rethinking of the aims and scope of the Task and in particular a consensus decision was taken to pass from the general aim of collecting and promoting (via the specialized Portal) existing Best Practices to the discovering, collecting and promoting, by means of the Portal, of “candidate best practices”, which are good or promising ones to become best practices in the near future.

Good practices searches were focused on the following key themes: Vaccination, Non-pharmaceutical steps, Health care workers, Gender issues, hard to reach groups, Communication and PH decision-making, and Didactic Projects concerning the role of SiS in Pandemics and Epidemics.

Eleven good practices have been collected so far: three on two-way communication, one on VIP civil society involvement, three on health mediation for hard to reach populations, three on vaccination campaigns and increasing awareness, and one on collaborations towards epidemic and pandemic prevention.

Best practices guidelines were developed from the collected practices. Some basic principles were identified as common across good practices, such as the direct and active involvement of civil society in key aspects of projects, co-ownership of initiatives and mutual learning between stakeholders and civil society. There was no “one-size-fits-all” solution apparent, and guidelines were classified by type of project. Seven large types of projects were identified, and were grouped according to the timing of their implementation in relation to an infectious disease epidemic: Prevention (before), Epidemic (during), and Aftermath (after), and key messages for each of these seven types of projects were extracted.

The Stakeholder Portal (SHP) was conceived as the gateway of the ASSET EU project for interested stakeholders to discuss how to reach a true Public Engagement in Public Health research and the Public Health initiatives concerning Epidemics, Pandemics and their prevention. It should foster discussions among Stakeholders on how to reach best practices in the involvement of Civil Society in these types of projects. The Stakeholder Portal was organized as a multi-social platform with 2 autonomous components: a Facebook group, allowing the SHP to interface with Civil Society, and a LinkedIn forum, allowing a constructive dialog with professionals of Public Health, Industry, and Academia. 3553 potentially interested stakeholders were contacted, and as of Dec 1st 2017, 1.3% had joined the Facebook group, and 1% had joined the LinkedIn group. The two SHP are continuously alimented with posts of interest on civil society and public health initiatives, inspired by the work of the ASSET consortium.

1 Introduction

Task 5.2 was central in the framework of the WP5, whose general aim was to enact practical mobilization and mutual learning (MML) actions at European, national, and local levels, both based on previous WPs (in particularly the task T3.2 on “Roadmap to Open and Responsible Research and Innovation in Pandemics” of WP3 and the WP4 on “citizen consultation”) and in coordination with the parallel work packages WP6 (“Policy Watch”) and WP7 (“Communication”).

The official Description of Work of T5.2, as described in the amended version of the accepted project application, was the following:

“T5.2 Best Practice Platform and Stakeholder Portal

Leader: IPRI Start: m25 End: m48

Contributors: NCIPD, TIEMS, UMFCD, HU, ZADIG

The Best Practice Platform (BPP) will be a web-based, ongoing, collection of best practices on SIS related issues in scientific and clinical research on pandemics. The BPP and will be sided by a Stakeholder Portal, which will provide a gateway for interested stakeholders to register their interest in becoming involved. The Stakeholder Portal will be organised for specific campaigns or consultations. Both the BPP and the Stakeholder Portal will be hosted by the ASSET web site. This task will be partly built on the outcomes of T3.2 Roadmap to Open and Responsible Research and Innovation in Pandemics. Best Practice Platform: the task leader will collect established best practices concerning the incorporation of SIS related issues in scientific and clinical research on pandemics. A key factor impacting the success of the Best Practice Platform will be the presence of a section devoted to developing best practice guidelines (BPGs).

These guidelines will be drafted by the task leader and validated through a consensus-building process among stakeholders. Organisations, institutions, universities, etc., which register themselves into the platform, will have the opportunity to be accredited by ASSET when they meet the research standards defined by a BPG, with awards of distinction presented to teams modelling comprehensive utilization of BPGs. In addition, a European recognition will be given to health professionals, researchers, public health authorities, etc. who begin to identify and spread best practices early on. Overall the BPP will thus serve to 1) Collect established best practices on SIS related issues in research on pandemics

2) Seek out and promote solutions that are already best practices but haven’t yet been widely adopted

3) Transfer knowledge of best practices among researchers, practitioners, institutions and organizations

3) Develop best practice guidelines.

4) Validate best practice guidelines.

5) Disseminate and encourage best practice adoption.

The inputs/outputs of the Task 5.2 can be summarized in the following Table:

Table 1 ***Main Interactions of Task 5.2 with other Tasks***

Feedings towards other tasks/WPs	Mainly, 5.2 informs some tasks of WP7 like 7.3 (website) and 7.4 (media office); of WP5 like T5.3; the future HLPF
Feedings necessary for task accomplishments from other tasks/WPs	5.2 receives input from 3.2
	5.2 receives input from WP2 tasks
	It is also related to HLPF

2 Framing Task 5.2 with respect to the previous work and established guidelines

As in all EU projects, the DoW has to be dynamically adapted to

- Put it in the framework of the project's previous research results
- Put it in the framework of the various project guidelines and key deliverables elaborated before the start of the Task
- Adapt it to the reality that is observed during the duration of the Task itself

2.1 Previous work and established guidelines

As far as the guidelines were concerned, the ASSET Strategic Plan (ASP) was our main reference. The ASP was based on six action lines that are the main RRI key-themes. Namely, indications for action for our Task and more in general for the whole WP5 had been collected and resumed in a single strategic line. In particular, Task 5.2 was mentioned in 5 out of the six action lines:

- **UNSOLVED QUESTIONS** typically connected with the Task **5.2**, from Task 2.2 and Task 3.2 that is the "Roadmap towards responsible and open, citizens-driven, research and innovation on vaccines and antiviral drugs". It complements the Strategic Plan (Task 3.1) because it reviews existing experiences of user driven innovation in the health and pharmaceutical sector to answer the question to what extent, and according to which conditions, user innovation is possible in the field of research and innovation on epidemic infectious diseases prevention and response. Where possible, existing initiatives, projects related to the involvement of "users" in epidemic infectious diseases prevention and response are mapped and referenced

- **PARTICIPATORY GOVERNANCE** To be tested in the **local initiatives (Task 5.3)** where the project will work out key messages targeted at specific risk groups (patients with cardiovascular disease, with lung diseases, mothers, and healthcare workers) on the benefits face **(Task 5.1)** where the project will join the main group that are conducting active discussion on that topic. The **BPP (Task 5.2)** will be deeply promoted on the same theme and potentially best practices worth to be published will be also be considered for the ASSET web site. Vigilance and attendance of authorities on social networks could reduce the risk. Thus, through the **BPP (5.2)** case-studies will be brought to their members on how authorities have a meaningful presence online so that they can recommend on social media presence by authorities during a crisis. **Local initiatives (5.3)** will help to understand ways to disseminate such an approach at local level, notably in order to prevent rumours.

- **ETHICS** [….] Particularly important will be the involvement of the **stakeholders' portal and the best practices platform (Task 5.2)**, where participants will be invited to identify best practices and then discuss ethical implication and feasibility in other contests. **Local initiatives (Task 5.3)** are expected to be an effective approach to convey inputs coming from citizens' consultation and the stakeholders' platform aiming to promote mobilization and mutual learning at local level and to enhance the transferability of the most effective policies and practice.

- **GENDER** (**low vaccination coverage in women**) [….] Another area to cover concerns the return of results through innovated science communication models **(best practices; Task 5.2)** with relevant stakeholders, from the related **portal (Task 5.2). (low studies on women**) **Best practices (Task 5.2)** on increasing number of studies on female representativeness in clinical trials and on women's experiences and attitudes to vaccinations will be explored. Several tools will be used to engage with relevant stakeholders in the field, such as the **stakeholder portal (Task 5.2); social media (Task 5.1) monitoring** will be carried out. (Scarce response by health system:/HCWs) to sensitize important stakeholders in the field and above all public health authorities by enhancing a constructive dialogue through the stakeholder portal to share best practices (Task 5.2). […]

- **ICOs (toward a law enforcement) [….]** Within the world of social networks, where ASSET is present, a discussion will be fostered, as well as in the project's **stakeholders portal (Task 5.2).**

As far as the research work accumulated within the lifetime of the project is concerned, our work has been greatly facilitated by the fact that IPRI was strongly involved in two key tasks of WP2 (namely, "unsolved scientific questions") and of WP3 ("ASSET roadmap"). The involvement of IPRI in these two tasks was substantial, a de-facto co-leader, as evidenced by the fact that the two manuscripts (one submitted and the other in preparation) on these tasks have the iPRI principal investigator in ASSET, Dr Alberto d'Onofrio, as co-corresponding author.

Task 2.2 "Reference guide of unsolved scientific questions related to pandemics and epidemics" stressed that the key unsolved scientific questions in Epidemics and Pandemics for which a larger potential for Science in Society exists mainly concern: the problem of two-way decision making and two-way communication, and the role of human behaviour in the spread and control of infectious diseases. On the whole, all are related to the "Post Trust Society" we are living in. Scarce possibility was envisaged for the direct collaboration of civil society in biotech projects related to infectious diseases.

The T3.2, "Roadmap to open and responsible research and innovation in pandemics", stressed that RRI and Public Engagement are still at their infancy as far as the Public Health research on the control of Infectious diseases is concerned, with one remarkable exception: AIDS. In general, the report stressed that "the public collaboration in research until now has been accidental".

Another important input was the Task 2.5 on "Gender issues in pandemics and epidemics". From this report, one can infer that there is a need of Best Practices aimed at a greater awareness of the risks related to epidemics and pandemics for women (both intrinsically and as family health decision makers and care givers), for elderly people and for hard to reach groups. Task 2.5 also stressed the relevance of post-trust social phenomena to be target by Best Practices.

The results of both T2.2 and T3.2 had shown without doubt that, respectively, the potential for RRI and the reality of Public Engagement were strongly more focused on Public Health research related issues concerning Epidemics and Pandemics than on the biotechnological research on the development of new vaccines.

3 The Adjustment of the Description of Work of Task 5.2

Task 5.2 needed a long and quite elaborate phase of work in order to update the content of its Description of Work in the light of the previous ASSET results.

3.1 A consensus definition of "Best Practice"

The starting point of the work on this Task consisted in the identification of a sufficiently unambiguous definition of what is a Best Practice (BP). This point is slightly less trivial than one might think, since multiple definitions of BP exist and most often they are context-dependent. The definition we proposed and that was validated by the ASSET consortium is the following:

A Best Practice is a Practice "that has **consistently** shown **results superior** to those achieved with other means, and that is used as a **benchmark**" (from: http://www.businessdictionary.com/definition/best-practice.html).

This and other definitions convey a series of important points:

- The fact that a BP has "**results superior** to those achieved with other means" implies that the "users" have a sufficiently large set of alternatives but they have designated that practice as BP for its superiority;
- The word **benchmark** conveys the meaning that there are continuously new practices that are standardly compared to the BP to assess their degree of excellence;
- The adverb **consistently** implies that the practice has revealed superior for a period that can be considered long for the applicative domain of interest. If this period can be quite short in some frameworks (social media for example), in the field of PH for Epidemics and Pandemics it is on the contrary medium/long.

3.2 The Risk Map and the Redefinition of the Description of Work

Based on the above premises and on further intensive preliminary researches, we outlined a series of actual and potential problems concerning the development of the Task 5.2, i.e. a "risk map" of possible critical problems for the work of Task 5.2. The key points of this map were the following:

- Defining criteria of good and of promising practices: to make an effort to reach a consensus in the consortium for the definition of good and of promising practices;
- Existence of insufficient number of good/promising practices. From the work on T2.3 and T2.2 it was quite evident that there was a paucity of best practices, and in particular no practices at all (at least publicly disseminated/communicated) concerning the Public Engagement in biotechnological fields concerning pandemics and epidemics. Thus, in theory, the risk existed that there were also an insufficient number of "good" practices to feed the BPP. This risk was lesser for promising practices;
- Developing best practice guidelines (BPGs): existence of sufficient scientific/technical material and personal feedbacks allowing to draft the BPG;
- Interest of SHs in active participation to the SH portals, availability of contacted institutions and persons in being engaged. A strategy of involvement of SHs has to be planned;
- Recognizing ASSET accreditation to bodies registered onto the platform when they meet research standards defined by a BPG, with awards of distinction presented to teams modelling comprehensive utilization of BPGs; Existence of institutions interested in registering. Bodies to be registered/awarded have to be officially recognized by EU and/or by EU member countries. Awarded teams must have high scientific and/or Public Health Profiles;
- Giving an additional European recognition to health professionals, researchers, public health authorities, etc. who begin to identify and spread best practices early on.

- Existence of institutions or persons interested in identifying and spreading the identified good/promising practices in order to form a consensus that can enable them to become best practices.

These issues were widely discussed, especially with the coordination institution (ISS) and with the communication leader (ZADIG). By means of these discussions, ASSET arrived to a consensus.

As far as the Description of Work of Task 5.2 was concerned, the consensus was that the task is quite misleading. Indeed, evidence available in literature Patient and Public Involvement (PPI) is largely not well taken into account and, on the whole, the DoW fits more with areas other than the one of interest in ASSET.

Moreover, in those different areas, the existing good/best practices are few and they generally cannot be adapted to the area characterized by the DOW of this Task. WP 3, and in particular Task 3.2, evidenced instead a remarkable amount of theoretical work, whose transition in Practices is “in progress”.

This implied a partial rethinking of the aims and scope of the Task and a consensus decision was taken to pass from the general aim of collecting and promoting (via the specialized Portal) existing Best Practices to the discovering, collecting and promoting, by means of the Portal, “candidate best practices”, which are good or promising ones to become best practices in the near future. It is noteworthy that such kind of fine-tuning is quite common for EU projects where the content of tasks scheduled for the second half of the lifespan of a project have to be readjusted on the basis of the findings obtained during the first part of the project.

The above-described shift was based on a feasibility issue at first, but it was also stressed that the whole activity assumed more interesting traits. It was stressed that an advanced phase will concern conceiving “Best Practices Guidelines” (to be used mainly after the project completion), but the first step had to focus on which areas to be highlighted and where ASSET researchers had to focus on. Moreover, it has been stressed that the above guidelines constitute an important part of the “heritage” of the ASSET project, i.e. they are meant to have an effective societal impact in the years following the end of the project.

Within the task log frame, it was stressed that some steps described in the DOW of the Task were not strongly connected. As a consequence, it was proposed that it would be prudent to first plan the design of a social page and to collect good practices on the identified topic areas (e.g. vaccines, two way-communication and decision-making in PH etc.). Only once a “critical mass” of debate and diffusion is created, then the available material can be enlarged and the portal activated. The risk, otherwise, is to build a non-robust and non-active Portal. Guidelines to be setup are on the top, but preliminary to them, other steps have to be enacted. Summarizing, this task had to be seen as very dynamic.

As far as the format to be adopted for the Stakeholder Portal (SHP) was concerned, there were no hints on how to implement it in the Description of Work. Thus, a consensus was reached focusing on the idea of not creating a separate website or a special section on the ASSET website, but to design and implement the Stakeholder Portal on social networks. Specifically, we chose Facebook and LinkedIn. The invitations to join the SHP had to be in first instance done by searching the ASSET interactive social database, which became thus the first source to involve relevant stakeholders.

3.3 The definition of Good and Promising Practices

According to what was planned in agreement on the aims of the Task, we reached a consensus on what are good and promising practices in the framework of the ASSET project. Types and categories of projects to be included in the Best Practices Platform were defined.

A good practice is a method that has shown **results** or, in case of "promising practices", **preliminary results** superior to those achieved with other means. In particular, **"good/promising practice"** will mean projects that are **in alignment with** previously identified **issues described in the Tasks of WP2 and in the Task 3.2** (the Task on **"ROADMAP"**).

A collection of best/good practices starts with a collection of examples of projects which included Civil Society in general, or important sectors of Civil Society, in some **active** manner during the inception/design phase, or the implementation phase, or the evaluation phase. Projects which involve Civil Society in a **passive** manner (such as analyses of social media posts) **without impact on policies/communication strategies** or which consider Civil Society only as the target of a programme (such as leaflet dissemination in general practitioners offices, without any other input from Civil Society) are not to be considered as best/good/promising practices.

The projects can be at any population level: international, European, national, regional, or community-based. The projects can **be finished, in progress, or in the inception phase**.

An important part of the activity has been devoted to delimit the areas of interest of the practices to be collected. This was based mainly on results of the work in the WP2 and in the Task 3.2 of WP3.

3.4 The scientific areas of the Good and Promising Practices

The identified key themes on which the search of good practices examples were focused are:

- **Vaccination:** trust rebuilding, trust monitoring, propensity to vaccinate
- **Non-pharmaceutical steps:** decreasing behaviours at risk and/or increasing risk-reducing behaviours (hand-washing, mask wearing, social distancing, school closures, travel restrictions)
- **Health care workers:** GPs involvement in prevention of infectious diseases, increasing the propensity of HCWs to get vaccinated and to adopt non-pharmacological preventive steps
- **Gender issues:** pregnant women, vaccination in women (including pregnant women)
- **Low income or ethnic minorities** (e.g. migrants, Roma communities)
- **Communication and PH decision-making. In particular two-way communication/decision in public health** (feedback): risk/ uncertainty/ outbreak communication, public involvement in counteracting/dispelling rumours and conspiracy theories

- **Didactic Projects** concerning the role of SiS in Pandemics and Epidemics
- SiS projects actively involving **special sectors of Civil Society**

Of course each Good/Promising Practice can belong to more than one of the above areas: they are not mutually exclusive.

The above list is to be intended as dynamic, and, as an example, the last two items were introduced during the work on the Task.

3.5 Documenting a Good or Promising Practice on the Best Practice Portal

As far as the design of the documentation of the Good Practices was concerned, it was decided that each best/good/promising practice has to be described in at least two documents.

The first had to be a synthetic "factsheet" describing the key practical points of the best/good/promising practice. For example: areas of the project (see above list of key focus of T5.2), start and end date of the project, the project leader or the person of contact, website of the project (if available) etc.

The second mandatory document had to be a clear and complete description of the practice. This document must contain links to other more extensive documents (textual or multimedia): press articles, PH reports (e.g. WHO or ECDC reports) on the practice, scientific papers etc.

When possible, other documents will be produced. Namely, written and/or multimedia interviews with key persons of each described practice. The interviews will focus particularly on the SiS content of their practices, and on the practical difficulties they encountered during their design and implementation.

Of course, the contents of the documents describing practices will be dynamic and they will be periodically updated.

3.6 Research Methodologies and preliminary Results

Based on methodologies elaborated in the fields of critical reviews and of meta-analyses, we devoted some efforts to design the internet search of the good practices, by individuating an exhaustive and dynamic list of keywords to be employed. We also established a number of search engines on which to perform the analysis, and of websites to be monitored.

To train ourselves, in the first phase of the search we made some experimental searches in areas not directly related to the T5.2, then we moved on to the "in topic" subjects.

From these preliminary searches, two important issues emerged:

1. The pool of potential good/promising practices that could be employed to feed the BPP is limited, although sufficient to populate it.
2. The vast majority of practices are National practices, and not documented in English or only indirectly documented in English.

These two points were important with respect to both the original DOW and the Risk Plan. On one hand, the first point was reassuring, showing that we avoided immediately stopping the Task (even after its re-adaptation from collecting best practices to good and promising practices). On the other hand, the second point showed that, by any means, the portal could document only a fraction of the effective world of good practices, limited to a few languages. Also, this important risk had not been considered in the ASSET project.

The search for good practices was conducted on multiple fronts. The base of the search strategy was the internet, with electronic searches on various databases, such as Scopus, ECDC, or WHO. A search strategy protocol was elaborated, indicating the main websites and journal to be searched, as well as keywords to be employed for the searches. We learned from the preliminary searches that the topic at hand was too wide for an unfocused search to yield adequate results. We therefore included in the search protocol a list of main themes and subthemes on Science in Society related issues on which to focus the search. The themes were selected in relation to issues identified in previous ASSET tasks (such as Task 3.2, Task 2.2). The search protocol is reproduced below.

3.6.1 Best Practices – Search Protocol

Objective

Identify best practices or good practices which could be candidate best practices of integrating civil society in public health projects concerning epidemics and pandemics, with a particular focus on influenza. Programs, initiatives, or interventions need to involve members of civil society in the design and/or implementation phases, and not consider them only from the point of view of target population.

Search parameters

Eligible documents included scientific articles, books, grey literature (theses), reports, and websites. The searches were done in English first and then, for each theme and subtheme, a second, more focused, search was performed in French, Romanian, and Italian.

Eligible documents referenced programs, initiatives, interventions, strategies or policies that included civil society in their design and/or implementation phases.

The results were not restricted to programs implemented in member states of the EU, in order to identify as many good practices as possible, which could have the potential to be translated to the EU context.

Eligible documents had to have been published between 2000 and the present day (Mai-July 2016).

Electronic searches of databases, search engines and specific journals were performed. **Table 2** lists the resources searched for eligible documents.

Key themes on Science in Society related issues were identified in previous tasks and are listed in **Table 3**.

For large databases (such as Scopus, Pubmed), three categories of search terms were combined to give results for each specific theme: civil society, infectious diseases, and the key theme or subtheme. For less developed search engines (such as CDC, ECDC websites), simplified search terms were used.

Complementary, non-systematic, searches were done by identifying civil society associations and looking for public health projects that they had previously been involved in.

Table 2. Resources searched

Name	**Description**
DATABASES	
Scopus	“Abstract and citation database of peer-reviewed literature”
Pubmed	“Biomedical literature database Medline, life science journals and online books”
CDC	Centers for disease control and prevention, USA
ECDC	European Center for Disease Prevention and Control
WHO	World Health Organization
WHO International Clinical Trials Registry Platform	Database of clinical trials
International longevity centre	“A think-tank impacting policy on longevity, ageing and population change”, UK
EMA	European Medicines Agency
Campbell library of systematic reviews	Systematic reviews on interventions in crime and justice, education, international development, and social welfare
Centre for reviews and dissemination	“Policy relevant research and innovative methods […] to improve population health”
The Cochrane library	Databases of systematic reviews on human health, controlled trials, health technology assessment
Index to theses (British and French)	Online repositories of doctoral theses

Zetoc	Database of the British Library’s electronic table of contents
Copac	Database of the catalogues of 90 major UK and Irish libraries
GAVI alliance	Global Vaccine Alliance, public-private partnership
Open Grey	Database of Grey Literature in Europe
JOURNALS	
Research Involvement and Engagement	Health and social care journal, “focussing on patient and wider involvement and engagement in research, at all stages”
Vaccine	Elsevier Journal on Vaccines
Infection Control and Hospital Epidemiology	“Peer-reviewed scientific articles for anyone involved with an infection control or epidemiology program in a hospital or healthcare facility”
WEB	
Google	web search engine

Table 3. Key themes and sub-themes researched

Vaccination	**Communication**	**Non-pharmaceutical steps**	**Health care workers**	**Gender issues**
trust re-building	2-way communication in PH	hand-washing	GP	pregnant women
trust monitoring	low-income and ethnic minorities	mask wearing	hospital personnel	low-income and ethnic minorities
propensity to vaccinate	risk, uncertainty and outbreak communication	social distancing		
low-income and ethnic minorities	counteracting/dispelling rumours and conspiracy theories	low-income and ethnic minorities		
effectiveness of vaccines				

Moreover, the fact that the vast majority of practices are National practices, and not documented in English or only indirectly documented in English, had a practical impact in the ASSET project. It implied that not only the consortium members that were involved in T5.2 had to collaborate to the Task, but also all consortium members were invited to collaborate by signalling good/promising national practices described in the national languages of the consortium members.

3.6.2 Good Practices week

For this reason we decided to launch “The Week of Good Practices” during which all scientific personnel working in ASSET were supposed to inform us about their knowledge of such Good Practices in their respective countries, and communicate them to the Task Leader of T5.2.

The Week of Good Practices took place from the 13th to the 19th of February 2017. Four contributions from ASSET Partners were received, out of which one initiative from Bulgaria (Vaksinko) was identified as a good practice and published on the platform.

In parallel with the above conceptual and practical activities, we also proceeded in the practical definition of the BPP as area of the ASSET website. In particular it has been stressed that the BPP has to be partially mirrored also in the Facebook page of ASSET and in the ASSET Twitter account.

3.7 Update of Aims of Task 5.2, of the Strategic approach

As it was clear from what we exposed in the previous sections, it has emerged that a deeper clarification concerning the DOW was necessary.

Namely, first it has been evidenced that the BPP has a double aim.

1. The original aim described in the DOW to archive and divulgate Best (in reality Good/Promising) Practices to both the Civil Society in EU and elsewhere, and to stakeholders of public health not directly involved in ASSET (e.g. a Stakeholder that finds the platform thanks to a web search via google)
2. The additional aim of being a source of information and, mainly, of debate for the Stakeholders Platform (SHP). For this reason the Good/Best Practices described in the BPP have to be not only informative, but also engaging enough for SHs.

The chosen strategic approach was fourfold and as follows:

- Validate Information and share all relevant information;
- Elaborate and validate a consensus process to establish which of the existing good practices on SIS for epidemics/pandemics can be considered as candidate Best Practices (BPs);

- Once the SH portal has been enacted (i.e. after the BPP has been populated by a sufficiently large number of good/promising practices), elaborate and validate a consensus process to actively involve stakeholders in the BPP). Jointly design ways to test/solve possible disagreements between stakeholders on candidate BPs;
- Always promote reflective practices to enlarge the portfolio of ideas.

The rearrangement of the general objectives of the Task 5.2 was conducted as in the following list:

- Collect good practices concerning SIS related issues in scientific and clinical research on pandemics.
- Promote solutions that are already best practices but haven't yet been widely adopted
- Establish which of the collected practices can be considered as candidate best practices
- Foster the activity of registered stakeholders on the portal
- Develop a section devoted to developing best practice guidelines (BPGs)
- Validate proposed guidelines through a consensus-building process among stakeholders involved in the portal
- Define and implement awards of distinction presented to teams modelling comprehensive utilization of BPGs.
- Implement awards of distinction presented to teams modelling comprehensive utilization of BPGs and validated through a consensus-building process among stakeholders
- European recognition will be given to health professionals, researchers, public health authorities, etc. who begin to identify and spread best practices early on
- Maximize BP Portal-related transfer knowledge of best practices among researchers, practitioners, institutions and organizations
- Disseminate and encourage best practice adoption
- Transfer knowledge of best practices among researchers, practitioners, institutions, organizations

As far as the methodologies of research are concerned, to enact the re-defined aims of the task T5.2 the following methods were selected:

- Design the literature and the web review. This will also involve a review of good practices pointed out in the reports of WP2 and any other deliverable and report produced in ASSET, and in related current and past EU projects (e.g. TELLME). The review will be up to some extent interactive because based on it we will stimulate an internal discussion in the ASSET communication platform
- Elaborate a consensus methodology to transform an existing practice into a best practice

- Define the characteristics of potential stakeholders that may be active on the portal
- Define methods to “spontaneously attract” stakeholders into the portal
- Define Criteria for the validation of the registration of spontaneously attracted stakeholders
- Review and discuss on the ASSET portal the current literature on the development of BP guidelines
- Define the research standards defined by a BPG,
- Define the awards of distinction presented to teams modelling comprehensive utilization of BPGs
- Most important Good Practices will be documented and reported to the task leader, and widely discussed among the task participants and (after a first discussion internal to the task) also by the ASSET community of practice via the internal ASSET platform. Then the Task Leader will manage the whole task and provide a consolidated report, as well as *interim* reports.
- Regular meetings among partners – face to face and virtual - will provide exchange of information, deeper coordination, review and internal evaluation.

3.8 Plan of practical activities

All enacted activity will involve all the partners of this task (IPRI, NCIPD, TIEMS, UMFCD, HU, ZADIG), in various degrees depending on the planned PMs, and all the other members of the consortium via frequent exchange of ideas in the ASSET Community of Practice platform.

Here were the planned activities of the present task:

1. Identify the preliminary list of Stakeholders that could be involved in the SHP
2. Analyse the preliminary list and identify the strategies to best approach and involve the identified stakeholders
3. Contact the identified stakeholders, by contacting Organizations, institutions, universities, etc.,
4. Design the structure of the BPP
5. Design the mechanisms of working of the BPP
6. Preliminary technical activities concerning the set-up of the BPP and of the SH portal (ZADIG)
7. Research of candidate BP
8. Elaboration of BP guidelines
9. Validation of BP guidelines
10. Discussion on the BPP

11. Tentative application and Feed-back
12. Give awards of distinction presented to teams modelling comprehensive utilization of BPGs
13. Give an European recognition to health professionals, researchers, public health authorities, etc. who begin to identify and spread best practices early on
14. Technical activities concerning the SH portal (ZADIG)

4 Good and Promising Practices

The Best Practices Platform assembled good examples of projects related to infectious diseases, where civil society was involved in an active manner during any or all phases of the project (inception/design, implementation, evaluation). The list of good practices on the platform is by no means exhaustive, and can be continually enriched with new good practices.

Here is the list of the eleven documented Good Practices that we collected and which are currently published on the BPP:

I. Two-way communication
   1. Citizen consultation – France
   2. Risk communication feedback during epidemic – New Zealand
   3. Feedback for designing targeted vaccination campaign – USA
II. VIP civil society involvement
   1. Lyon vaccination campaign “Immuniser Lyon” – France
III. Health mediation for hard to reach populations
   1. Health mediation for Roma communities – Romania (initial implementation)
   2. Health mediation for Roma communities – Bulgaria
   3. Health mediation - France
IV. Increasing awareness – vaccination campaigns
   1. Italian Chart for promotion of vaccinations – Italy
   2. European Immunization Week – Europe
   3. Vaksinko - Bulgaria
V. Collaborations towards prevention
   1. The Coalition for Epidemic Preparedness Innovations (CEPI) - worldwide

For each good practice, a factsheet resuming the main information regarding the project was uploaded together with the description of the latter. We also sent invitations for participation to interviews to leaders of projects described in the good practices, in order to have a more detailed and insightful view of the projects themselves but also of the lessons learned and challenges encountered. Four projects leaders participated to the interviews, and their answers are published on the Best Practices Platform.

Some of the project examples we identified did not respect the selection criteria to be considered a good practice or a candidate best practice. Indeed, the active involvement of civil society in the projects was a strict requirement for selection of good practices. The following is an example of a project that was not selected as a good practice:

Sanofi digital clinical trials *(https://lehub.sanofi.com/en/innovation-en/sanofi-launches-digital-clinical-trials-to-improve-recruitment-and-reduce-trial-times/)*

This was a project aimed at improving participation in clinical trials by creating digital decentralized clinical trials, to which participants could be recruited and enrolled and participate from their homes. This could address shortcomings of traditional trials, reduce burden for patients, as well as improve data representativeness of the actual population, as it would help recruit people who would not normally participate in clinical trials (e.g. those living in remote areas etc.).

Sanofi's digital clinical trials project, while being a worthwhile endeavour, did not however engage civil society in a way that would correspond to a promising practice. It only acts as a tool created to help participation of civil society in clinical trials.

Challenges arose not only in finding examples of projects in which civil society was involved actively, but also sometimes in clearly identifying what exactly the role of civil society was during a project. Some projects lacked sufficient documentation, or had documentation in languages other than the languages spoken among iPRI researchers (English, French, Italian or Romanian). The language barrier was somewhat mitigated by the set-up of the "Good Practices Week" described above. However, the "Good Practices Week" yielded only one new good practice.

Potential good practices were also searched for through discussions with colleagues about Science with and for Society related issues and through any tangential research opportunity.

Beginning December 2017, there were 11 good practices identified and collected on the Best Practices Platform on the ASSET website (http://www.asset-scienceinsociety.eu/outputs/best-practice-platform). Each good practice has a detailed description on the website, plus a factsheet summarising its characteristics. People representing each good practice were contacted and invited to participate to an interview, in order to have a more detailed and direct account of the good practices, specifically of challenges met and overcome during its implementation. **Table 4** summarizes the characteristics of the collected good practices.

Table 4 – Characteristics of collected good practices

Name of good practice	Country	Period	Level	Documentation	Evaluation	Role of civil society	Interview	Themes
Carta Italiana	Italy	2015-ongoing	local & national	website in Italian	no	project initiators and	yes	-vaccination

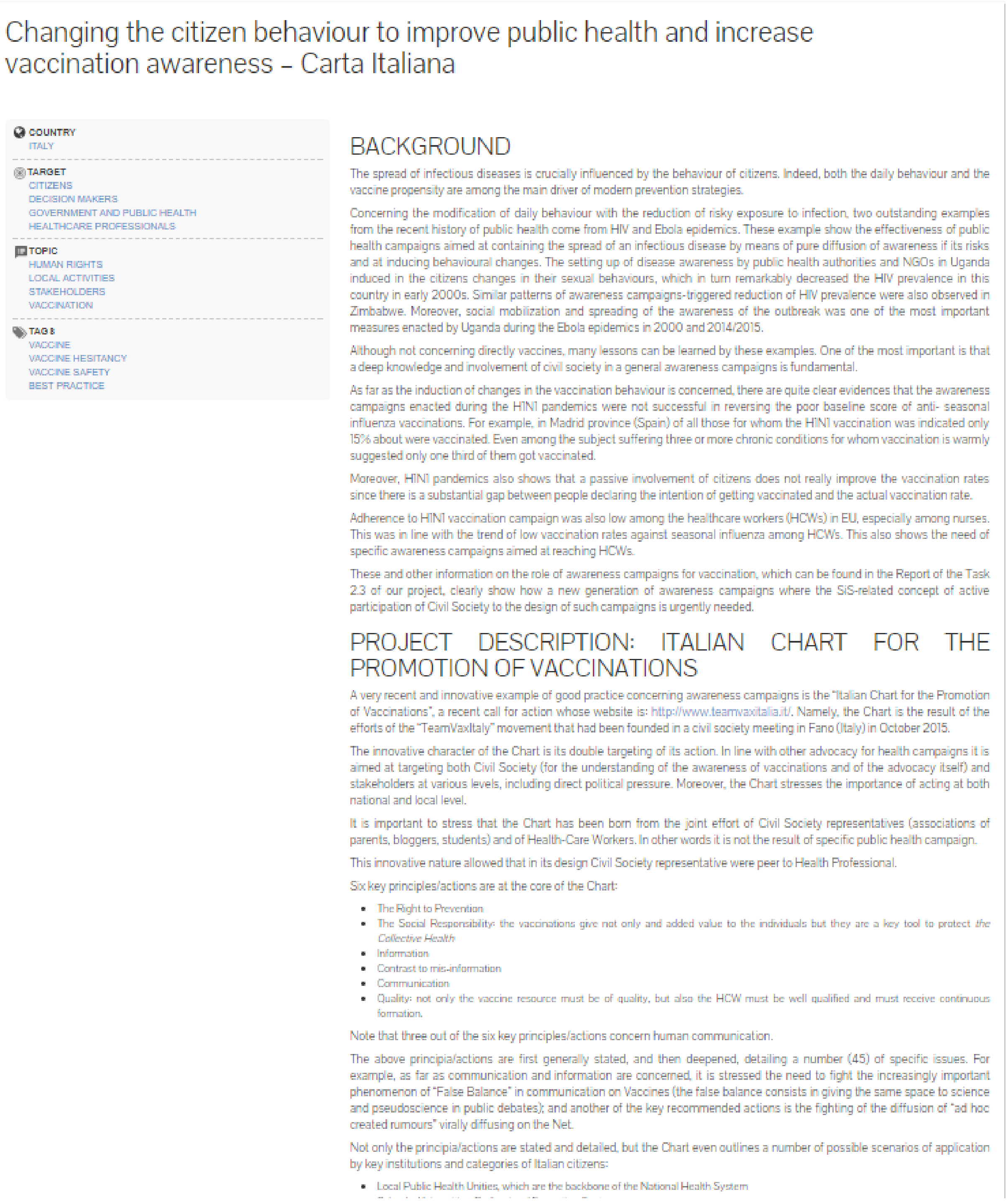
						managers		
Health Mediation Bulgaria	Bulgaria	2001-ongoing	local & national	website in English and Bulgarian	internal - yes external - no	-project initiators and managers -mediators	yes	-hard to reach groups -prevention -mediation
Population consultation, two-way communication and decision, France	France	2016	national	website in French	no	-citizen consultation	yes	2-way communication
Health mediation France	France	2011-ongoing	local & national	website in French	yes	-project initiators and managers -mediators	no	-hard to reach groups -prevention -mediation
The Health mediators project in Romania (RHM – Roma Health Mediators)	Romania	1996-ongoing	local & national	- website in English and Romanian - report in English	yes	-project initiators and managers -mediators	no	-hard to reach groups -prevention -mediation
Population consultation, two-way communication and decision in New Zealand	New Zealand	2010	local	scientific article in English	no	focus groups	no	2-way communication
Population consultation, two-way communication and decision in USA	USA	2009	local & national	website in English	no	-surveyed -focus groups	no	2-way communication
European	EU	2005-	Europea	website in	yes	active	yes	vaccination

Immunization Week		ongoing	n region	English		partners		
Immuniser Lyon	France	2015-2016	local	website in French	no	-active partners -VIP message communicators	yes	vaccination
Coalition for Epidemic Preparedness Innovations (CEPI)	world-wide	2017-ongoing	inter-national	website in English	no	active partners	no	vaccine development
Vaksinko : an informational campaign about vaccines in Bulgaria	Bulgaria	2016-ongoing	national	website in Bulgarian	no	active partners	no	vaccination

In the following Section: **“Good Practices Descriptions”**, good practices and corresponding documents are listed in the order of publication on the platform. For each good practice, a screenshot of the published practice on the BPP, the factsheet associated, the descriptive text of the practice as well as the text of the interview of the project manager/leader (when applicable) can be found.

5 Good Practices Description

5.1 Changing the citizen behaviour to improve public health and increase vaccination awareness – Carta Italiana



Changing the citizen behaviour to improve public health and increase vaccination awareness – Carta Italiana

COUNTRY
ITALY

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
HUMAN RIGHTS
LOCAL ACTIVITIES
STAKEHOLDERS
VACCINATION

TAGS
VACCINE
VACCINE HESITANCY
VACCINE SAFETY
BEST PRACTICE

BACKGROUND

The spread of infectious diseases is crucially influenced by the behaviour of citizens. Indeed, both the daily behaviour and the vaccine propensity are among the main driver of modern prevention strategies.

Concerning the modification of daily behaviour with the reduction of risky exposure to infection, two outstanding examples from the recent history of public health come from HIV and Ebola epidemics. These example show the effectiveness of public health campaigns aimed at containing the spread of an infectious disease by means of pure diffusion of awareness if its risks and at inducing behavioural changes. The setting up of disease awareness by public health authorities and NGOs in Uganda induced in the citizens changes in their sexual behaviours, which in turn remarkably decreased the HIV prevalence in this country in early 2000s. Similar patterns of awareness campaigns-triggered reduction of HIV prevalence were also observed in Zimbabwe. Moreover, social mobilization and spreading of the awareness of the outbreak was one of the most important measures enacted by Uganda during the Ebola epidemics in 2000 and 2014/2015.

Although not concerning directly vaccines, many lessons can be learned by these examples. One of the most important is that a deep knowledge and involvement of civil society in a general awareness campaigns is fundamental.

As far as the induction of changes in the vaccination behaviour is concerned, there are quite clear evidences that the awareness campaigns enacted during the H1N1 pandemics were not successful in reversing the poor baseline score of anti- seasonal influenza vaccinations. For example, in Madrid province (Spain) of all those for whom the H1N1 vaccination was indicated only 15% about were vaccinated. Even among the subject suffering three or more chronic conditions for whom vaccination is warmly suggested only one third of them got vaccinated.

Moreover, H1N1 pandemics also shows that a passive involvement of citizens does not really improve the vaccination rates since there is a substantial gap between people declaring the intention of getting vaccinated and the actual vaccination rate.

Adherence to H1N1 vaccination campaign was also low among the healthcare workers (HCWs) in EU, especially among nurses. This was in line with the trend of low vaccination rates against seasonal influenza among HCWs. This also shows the need of specific awareness campaigns aimed at reaching HCWs.

These and other information on the role of awareness campaigns for vaccination, which can be found in the Report of the Task 2.3 of our project, clearly show how a new generation of awareness campaigns where the SiS-related concept of active participation of Civil Society to the design of such campaigns is urgently needed.

PROJECT DESCRIPTION: ITALIAN CHART FOR THE PROMOTION OF VACCINATIONS

A very recent and innovative example of good practice concerning awareness campaigns is the "Italian Chart for the Promotion of Vaccinations", a recent call for action whose website is: http://www.teamvaxitalia.it/. Namely, the Chart is the result of the efforts of the "TeamVaxItaly" movement that had been founded in a civil society meeting in Fano (Italy) in October 2015.

The innovative character of the Chart is its double targeting of its action. In line with other advocacy for health campaigns it is aimed at targeting both Civil Society (for the understanding of the awareness of vaccinations and of the advocacy itself) and stakeholders at various levels, including direct political pressure. Moreover, the Chart stresses the importance of acting at both national and local level.

It is important to stress that the Chart has been born from the joint effort of Civil Society representatives (associations of parents, bloggers, students) and of Health-Care Workers. In other words it is not the result of specific public health campaign.

This innovative nature allowed that in its design Civil Society representative were peer to Health Professional.

Six key principles/actions are at the core of the Chart:

- The Right to Prevention
- The Social Responsibility: the vaccinations give not only and added value to the individuals but they are a key tool to protect *the Collective Health*
- Information
- Contrast to mis-information
- Communication
- Quality: not only the vaccine resource must be of quality, but also the HCW must be well qualified and must receive continuous formation.

Note that three out of the six key principles/actions concern human communication.

The above principia/actions are first generally stated, and then deepened, detailing a number (45) of specific issues. For example, as far as communication and information are concerned, it is stressed the need to fight the increasingly important phenomenon of "False Balance" in communication on Vaccines (the false balance consists in giving the same space to science and pseudoscience in public debates); and another of the key recommended actions is the fighting of the diffusion of "ad hoc created rumours" virally diffusing on the Net.

Not only the principia/actions are stated and detailed, but the Chart even outlines a number of possible scenarios of application by key institutions and categories of Italian citizens:

- Local Public Health Unities, which are the backbone of the National Health System

5.1.1 Factsheet

GOOD PRACTICE NAME: Italian Chart for the Promotion of Vaccinations

MAIN THEME: VACCINATION

SPECIFIC Sub-THEME: CHANGING THE CITIZENS BEHAVIOR TO IMPROVE PUBLIC HEALTH

MAIN OBJECTIVES: Increasing the awareness of vaccinations: in Civil Society, media and among professional of public health (PH officers and health-care workers)

KEYWORDS: VACCINATION, AWARENESS, CHART, CALL FOR ACTION, CIVIL SOCIETY, HEALTH-CARE WORKERS, PH DECISORS, POLITICAL DECISORS, COMMUNICATION, INFORMATION, MIS-INFORMATION, RUMORS, INTERNET, QUALITY, FALSE BALANCE, SCIENCE VS PSEUDO-SCIENCE

START DATE: October 2015

END DATE:

KEY OBJECTIVES:

WEBSITE: http://www.teamvaxitalia.it/

CONTACT PERSONS (mail): teamvaxitalia@gmail.com

PROJECT INITIATORS: Several actors of civil-society

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: BOTH

5.1.2 Background

The spread of infectious diseases is crucially influenced by the behaviour of citizens. Indeed, both the daily behaviour and the vaccine propensity are among the main driver of modern prevention strategies.

Concerning the modification of daily behaviour with the reduction of risky exposure to infection, two outstanding examples from the recent history of public health come from HIV and Ebola epidemics. These example show the effectiveness of public health campaigns aimed at containing the spread of an infectious disease by means of pure diffusion of awareness if its risks and at inducing behavioural changes. The setting up of disease awareness by public health authorities and NGOs in Uganda induced in the citizens changes in their sexual behaviours, which in turn remarkably decreased the HIV prevalence in this country in early 2000s. Similar patterns of awareness campaigns-triggered reduction of HIV prevalence were also observed in Zimbabwe. Moreover, social mobilization and spreading of the awareness of the outbreak was one of the most important measures enacted by Uganda during the Ebola epidemics in 2000 and 2014/2015.

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8.1.3 Project description: Italian Chart for the Promotion of Vaccinations

A very recent and innovative example of good practice concerning awareness campaigns is the “Italian Chart for the Promotion of Vaccinations”, a recent call for action whose website is: http://www.teamvaxitalia.it/

Namely, the Chart is the result of the efforts of the “TeamVaxItaly” movement that had been founded in a civil society meeting in Fano (Italy) in October 2015

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It is important to stress that the Chart has been born from the joint effort of Civil Society representatives (associations of parents, bloggers, students) and of Health-Care Workers. In other words it is not the result of specific public health campaign.

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Six key principles/actions are at the core of the Chart:

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- Contrast to mis-information
- Communication
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Not only the principia/actions are stated and detailed, but the Chart even outlines a number of possible scenarios of application by key institutions and categories of Italian citizens:

- Local Public Health Unities, which are the backbone of the National Health System
- Schools, Universities, Professional Formation Centres
- Healthcare Workers
- Civil Society
- Journalists/Bloggers

For each category a list of key points are listed, taken from the detailed list of principles/actions.

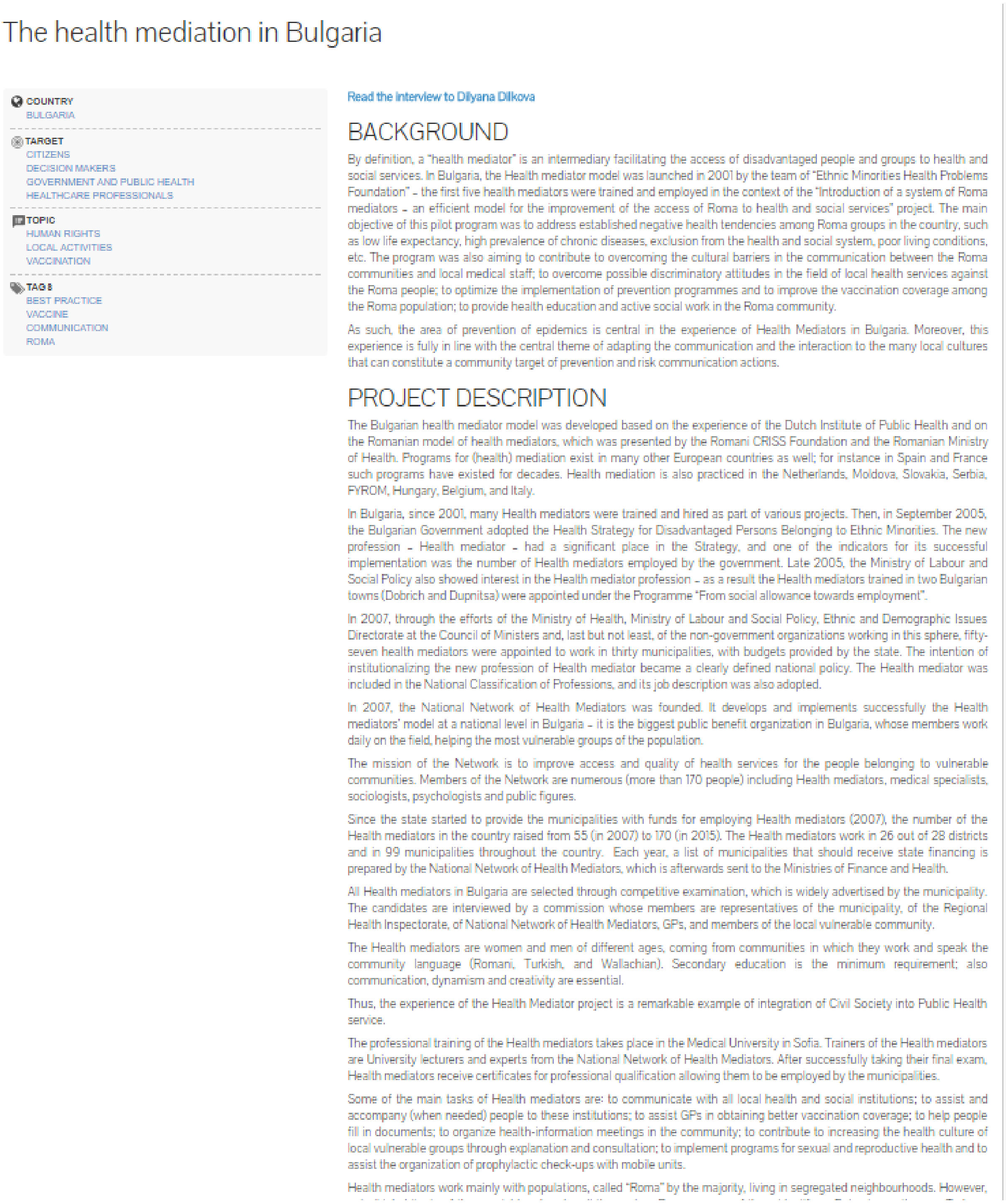
The website provides not only internal material (and namely, of course, a PDF version of the Chart) but also external toolkits, developed by other Italian initiatives, or international ones (in such a case, translated in Italian)

Of course, the chart is meant as a “work in progress”, both in its diffusion and in its content.

5.1.4 Status of the project

The project is still ongoing.

5.2 The health mediation in Bulgaria



The health mediation in Bulgaria

COUNTRY
BULGARIA

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
HUMAN RIGHTS
LOCAL ACTIVITIES
VACCINATION

TAGS
BEST PRACTICE
VACCINE
COMMUNICATION
ROMA

Read the interview to Dilyana Dilkova

BACKGROUND

By definition, a "health mediator" is an intermediary facilitating the access of disadvantaged people and groups to health and social services. In Bulgaria, the Health mediator model was launched in 2001 by the team of "Ethnic Minorities Health Problems Foundation" – the first five health mediators were trained and employed in the context of the "Introduction of a system of Roma mediators – an efficient model for the improvement of the access of Roma to health and social services" project. The main objective of this pilot program was to address established negative health tendencies among Roma groups in the country, such as low life expectancy, high prevalence of chronic diseases, exclusion from the health and social system, poor living conditions, etc. The program was also aiming to contribute to overcoming the cultural barriers in the communication between the Roma communities and local medical staff; to overcome possible discriminatory attitudes in the field of local health services against the Roma people; to optimize the implementation of prevention programmes and to improve the vaccination coverage among the Roma population; to provide health education and active social work in the Roma community.

As such, the area of prevention of epidemics is central in the experience of Health Mediators in Bulgaria. Moreover, this experience is fully in line with the central theme of adapting the communication and the interaction to the many local cultures that can constitute a community target of prevention and risk communication actions.

PROJECT DESCRIPTION

The Bulgarian health mediator model was developed based on the experience of the Dutch Institute of Public Health and on the Romanian model of health mediators, which was presented by the Romani CRISS Foundation and the Romanian Ministry of Health. Programs for (health) mediation exist in many other European countries as well; for instance in Spain and France such programs have existed for decades. Health mediation is also practiced in the Netherlands, Moldova, Slovakia, Serbia, FYROM, Hungary, Belgium, and Italy.

In Bulgaria, since 2001, many Health mediators were trained and hired as part of various projects. Then, in September 2005, the Bulgarian Government adopted the Health Strategy for Disadvantaged Persons Belonging to Ethnic Minorities. The new profession – Health mediator – had a significant place in the Strategy, and one of the indicators for its successful implementation was the number of Health mediators employed by the government. Late 2005, the Ministry of Labour and Social Policy also showed interest in the Health mediator profession – as a result the Health mediators trained in two Bulgarian towns (Dobrich and Dupnitsa) were appointed under the Programme "From social allowance towards employment".

In 2007, through the efforts of the Ministry of Health, Ministry of Labour and Social Policy, Ethnic and Demographic Issues Directorate at the Council of Ministers and, last but not least, of the non-government organizations working in this sphere, fifty-seven health mediators were appointed to work in thirty municipalities, with budgets provided by the state. The intention of institutionalizing the new profession of Health mediator became a clearly defined national policy. The Health mediator was included in the National Classification of Professions, and its job description was also adopted.

In 2007, the National Network of Health Mediators was founded. It develops and implements successfully the Health mediators' model at a national level in Bulgaria – it is the biggest public benefit organization in Bulgaria, whose members work daily on the field, helping the most vulnerable groups of the population.

The mission of the Network is to improve access and quality of health services for the people belonging to vulnerable communities. Members of the Network are numerous (more than 170 people) including Health mediators, medical specialists, sociologists, psychologists and public figures.

Since the state started to provide the municipalities with funds for employing Health mediators (2007), the number of the Health mediators in the country raised from 55 (in 2007) to 170 (in 2015). The Health mediators work in 26 out of 28 districts and in 99 municipalities throughout the country. Each year, a list of municipalities that should receive state financing is prepared by the National Network of Health Mediators, which is afterwards sent to the Ministries of Finance and Health.

All Health mediators in Bulgaria are selected through competitive examination, which is widely advertised by the municipality. The candidates are interviewed by a commission whose members are representatives of the municipality, of the Regional Health Inspectorate, of National Network of Health Mediators, GPs, and members of the local vulnerable community.

The Health mediators are women and men of different ages, coming from communities in which they work and speak the community language (Romani, Turkish, and Wallachian). Secondary education is the minimum requirement; also communication, dynamism and creativity are essential.

Thus, the experience of the Health Mediator project is a remarkable example of integration of Civil Society into Public Health service.

The professional training of the Health mediators takes place in the Medical University in Sofia. Trainers of the Health mediators are University lecturers and experts from the National Network of Health Mediators. After successfully taking their final exam, Health mediators receive certificates for professional qualification allowing them to be employed by the municipalities.

Some of the main tasks of Health mediators are: to communicate with all local health and social institutions; to assist and accompany (when needed) people to these institutions; to assist GPs in obtaining better vaccination coverage; to help people fill in documents; to organize health-information meetings in the community; to contribute to increasing the health culture of local vulnerable groups through explanation and consultation; to implement programs for sexual and reproductive health and to assist the organization of prophylactic check-ups with mobile units.

Health mediators work mainly with populations, called "Roma" by the majority, living in segregated neighbourhoods. However,

5.2.1 Factsheet

GOOD PRACTICE NAME: HEALTH MEDIATION (NATIONAL NETWORK OF HEALTH MEDIATORS)

MAIN THEME: VACCINATION AND PREVENTION

SPECIFIC Sub-THEME: Health mediation; increasing awareness of vaccinations in hard to reach populations, targeting the Public Health Actions and Risk communication to the cultures forming a given community

COUNTRY: BULGARIA

KEYWORDS: HEALTH MEDIATION, VACCINATION, VULNERABLE GROUPS, HARD TO REACH POPULATION, ETHNIC MINORITIES, ROMA POPULATION, PREVENTION, COMMUNICATION, AWARENESS, BEHAVIOR CHANGE, ADAPTING PH MESSAGES/ACTIONS

START DATE: 2001

END DATE: Still running

KEY OBJECTIVES:

- Improve access and quality of health services for vulnerable communities
- Changing behaviour of vulnerable groups through information and regular check-ups
- Optimize implementation of prevention programmes and vaccination coverage among hard to reach communities
- Create a link between these vulnerable communities and health and social institutions

WEBSITE: http://www.zdravenmediator.net/

CONTACT PERSONS (email) :

PETUR TSVETANOV petartsvetanov@zdravenmediator.net

info@zdravenmediator.net

PROJECT INITIATORS: Ministry of Health, Ministry of Labour and Social Policy, Ethnic and Demographic Issues Directorate at the Council of Ministers

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: BOTH

5.2.2 Background

By definition, a "health mediator" is an intermediary facilitating the access of disadvantaged people and groups to health and social services. In Bulgaria, the Health mediator model was launched in 2001 by the team of "Ethnic Minorities Health Problems Foundation" – the first five health mediators were trained and employed in the context of the "Introduction of a system of Roma mediators – an efficient model for the improvement of the access of Roma to health and social services" project. The main objective of this pilot program was to address established negative health tendencies among Roma groups in the country, such as low life expectancy, high prevalence of chronic diseases, exclusion from the health and social system, poor living conditions, etc. The program was also aiming to contribute to overcoming the cultural barriers in the communication between the Roma communities and local medical staff; to overcome possible discriminatory attitudes in the field of local health services against the Roma people; to optimize the implementation of prevention programmes and to improve the vaccination coverage among the Roma population; to provide health education and active social work in the Roma community.

As such, the area of prevention of epidemics is central in the experience of Health Mediators in Bulgaria. Moreover, this experience is fully in line with the central theme of adapting the communication and the interaction to the many local cultures that can constitute a community target of prevention and risk communication actions.

5.2.3 Project description

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All Health mediators in Bulgaria are selected through competitive examination, which is widely advertised by the municipality. The candidates are interviewed by a commission whose members are representatives of the municipality, of the Regional Health Inspectorate, of National Network of Health Mediators, GPs, and members of the local vulnerable community.

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Health mediators work mainly with populations, called "Roma" by the majority, living in segregated neighbourhoods. However, not all inhabitants of these neighbourhoods call themselves Roma – some of them identify as Bulgarians, others as Turks or Romanians. They speak different languages and have different religions.

As previously mentioned, the position of health mediators is aimed at optimizing the implementation of prevention programmes and increasing vaccination coverage among the Roma population. Some of the prevention-related projects of the NNHM (National Network of Health Mediators) are listed below.

5.2.4 Projects involving Health Mediators in Bulgaria

Initiative for Health and Vaccination

The project was implemented under the patronage of the Parliamentary Committee on Health and the Council of Ministers (National Council for Cooperation on Ethnic and Integration Issues). It started in 2010, as the measles outbreak in Bulgaria affected mainly Roma communities – 92% of the reported cases were in the Roma population. During the epidemic, national and regional meetings were held. The main objectives of the project were:

1. To improve health access to Roma communities by cooperation between health mediators, GPs, and Regional Health Inspectorate representatives
2. To extend the vaccination coverage among hard to reach groups;
3. To raise awareness of benefits and safety of vaccines.

Health mediators had an active role during the measles outbreak and its containment.

Health Promotion & Preventive Maternal and Child Health Care

The project was implemented by Open Society Institute – Sofia, ICON Institute (Germany), the Ethnic Minorities Health Problems Foundation and the Bulgarian Family Planning Association. The project aimed to improve access to preventive health services for women and children of ethnic minorities, with a focus on Roma. Several preventive clinical examinations with mobile units were undertaken in previously chosen locations. Meetings and discussions were conducted with families and youth, emphasizing the importance of preventive medical examinations. Both local communities and institutions (such as RHS, RIHPC, and NGOs) were involved, and families and youth underwent training (in two regions).

Let's talk about protection – a communication guide on childhood vaccination

In the period 2012 – 2014, the National Network of Health Mediators and the National Centre of Infectious and Parasitic Diseases started co-working on this project, financed by ECDC. The main goal of the project was to enhance the communication between health workers (GP's, paediatric specialists, nurses and health mediators) and families who were reserved towards, or refused mandatory vaccination. A Handbook aimed at helping parents to understand vaccination and supporting their choice to get their children protected was prepared by ECDC and adapted in Bulgarian – it included materials about diseases, vaccines' ingredients, their safety, answers to the most frequently asked questions related to the use of vaccines that parents had, etc. In addition, a study focusing on factors of vaccine refusal was conducted.

Personal Hygiene and Sanitation Education Campaign

In 2015, the National Network of Health Mediators started developing a Handbook focused on hygiene, as primary non-pharmacological step for prevention of epidemics and pandemics. A workshop was organized and the main discussed topics were: transmission of diseases, introducing hygiene topics and unsafe practices in Roma neighbourhoods. Participants proposed different materials for the educational Handbook. The campaign is continuing in 2016 and focusing on training of Health mediators for the usage of the developed materials.

In the past several years, many Health mediators started, among other activities, working in local hospitals. They were invited by hospital directors to facilitate the communication between patients and hospital staff, mainly in maternity and paediatric wards. The main problem was the tension arising between patients and staff because of some cultural differences. Additionally, the low level of health awareness and, in some cases, the difficulty encountered by patients to understand doctor's prescriptions was problematic. Employing Health mediators in hospitals showed to be very successful, also in economic terms, and is becoming more and more popular in the country.

5.2.5 Lessons learned and challenges

The National Network of Health Mediators works in partnership with organizations and institutions developing mediation programs in Europe through different projects. Some of the main aims of these partnerships are the strengthening of mediation programs in Europe and the exchange of experience and good practices between mediators and coordinators of mediation programs from different countries.

One of the strengths of the Bulgarian Health mediation model is the requirement for obligatory secondary education for each of the candidates for Health mediator. Another strength of the program is that each Health mediator is selected through fair competition, by a commission with representative from the Network of Health Mediators. In this way, the transparency and the quality of the selection are ensured. The possibility for both women and men to become Health mediators is also an asset – depending on the community and in certain neighbourhoods, men are considered to be in a better position to communicate health-related messages.

However, there are still some challenges to overcome, such as the inconsistent financing and/or contracts e.g. health mediators can work sometimes without being paid up to 3 months, the time it takes for the contract to be finalized. Moreover, salaries remain low with an average of 165€/month, ranging from 153 to 200 euros and depending on each municipality (Schaaf, 2011). Furthermore, providing adequate supervision of Health Mediators is one of the most important component of the success of such a project. Even if providing this supervision by allocating supplementary funds requires a large financial investment, it is essential for the program. Adequate supervision may also improve Health Mediators' effectiveness, as it is known that poor supervision can be associated with low motivation and decreased efficiency.

5.2.6 Status of the project

The Health Mediation project in Bulgaria is still ongoing, its model and successful development and institutionalization throughout the years served as example for developing mediation programs in other countries as well – Slovakia, Serbia, and FYROM.

Additional information on the program can be accessed via the following sources:

- Official website of NNHM: www.zdravenmediator.net
- Short video "Profession Health mediator" - https://youtu.be/PExp0pfH6nE
- Article, Vaccines Today: http://www.vaccinestoday.eu/vaccines/bridging-the-gap-health-mediators-help-reach-roma/ , 20 November 2013

5.2.7 References

Schaaf M. Roma Health Mediators: Successes and Challenges 2011.

5.2.8 Interwiew with Dilyana Dilkova

Name of the Best Practice: Health mediation in Bulgaria

Name of the person of contact: *Dilyana Dilkova – Member of the Managing Board, National Network of Health Mediators;* d.dilkova@gmail.com

Q1: How did this initiative start? What were the needs it addressed?

A: The introduction of the profession of the health mediator (HM) in Bulgaria started 23 years ago as a result of the work of a neurology professor – prof. Ivaylo Tournev. At that time, he travelled throughout Bulgaria in search of patients suffering neuromuscular diseases which led to serious invalidity. Entering in numerous Roma communities, prof. Tournev found out their dramatic social situation – poverty, poor living conditions, lack of access to healthcare and social workers; low health literacy; lack of identity cards in some cases. In order to help these people get diagnosed and receive proper medication, it turned out that their social problems needed to be addressed first. In that moment, the idea emerged that people from those communities who were more educated should be trained to help others reach health and social services. Then, in 2001, started the first project for HMs – the first five HMs were trained and started work in the Roma neighbourhood of the town of Kjustendil.

Q2: Can you describe how civil society was included in your project?

A: The project for introducing the position of the health mediator in Bulgaria was in itself a civil society initiative set up by the Ethnic Minorities Health Problems Foundation and its chairman prof. Ivaylo Tournev. Later, this mission was supported by other civil society organizations, such as the Bulgarian Family Planning Association. Many Roma NGOs also developed projects focused on health mediation in the first years of the introduction of the new profession. The institutionalization of the health mediators in 2007 was a direct result of years of advocacy with state institutions on behalf of the civil sector.

Q3: Why do you think it is important to include civil society in your project?

A: Civil society, when it functions well, performs several very important functions that could contribute to better state governance and better policies on state or local level. Among these functions is the possibility to represent the point of view of the weakest and most vulnerable members of society; to be a watchdog against violations on behalf of institutions; to increase the awareness of people with regard to their rights and responsibilities, etc. The National Network of Health Mediators (NNHM) has always counted on the voice of the local representatives of civil society. This is one of the reasons why our efforts with regards to the process of selection of new HMs have always been directed towards ensuring transparent procedure – for several years already all state-funded HMs are selected by commissions including representatives from the municipality, the Regional Health Inspection, NNHM representatives, local medical services provider and representative of local Roma NGO and/ or representative of the local Roma community.

Q4: What is the role of health mediators in your country, in the context of the Health Mediators project?

A: The HMs are women and men of different age, they originate from the communities in which they work and speak the community language (Romani, Turkish). They have graduated secondary education as a minimum and are communicative, dynamic and creative persons. They are trusted by the communities. The HMs act as intermediaries who facilitate the access of persons or groups in disadvantaged positions to healthcare and social services. In their daily work the HMs provide health or social information; organize and carry out health information gatherings; collaborate with GPs on issues like prophylaxis and vaccination; accompany clients to health or social institutions and help them fill in documentation or understand the prescriptions of the doctor; follow up families with chronically ill members; provide information on family planning and have a special focus on young mothers, health uninsured pregnant women, and children.

In 2007, the HMs were officially included in the Classificatory of Professions; their training started to take place in Medical Colleges and the state started to pay their salaries. The first 56 HMs were appointed in Bulgarian municipalities.

Q5: How does this work? Can you give more details?

A: The profession "Health mediator" succeeded to make its reputation in Bulgaria because it addresses problems related to poor health information and culture, existing myths for certain diseases and their treatment in the isolated communities, the lack of or the irregular immunizations among vulnerable groups. One of the key factors for HM's success is the fact that they belong to the community they work for. They help people overcome their prejudices and fears, gain their trust and contribute to community development.

Q6: How many Health mediators are working at the present?

A: In 2017 the State supports the salaries of 215 HMs; in 2018 their number will increase to reach 230 HMs working in 117 municipalities.

Q7: Can you give us some specific examples of initiatives / projects / campaigns Health mediators have worked on?

A: Within the peak of the European measles epidemic in 2010 (in Bulgaria about 24 000 people, mainly Roma, were affected and 24 children died) NNHM was one of the key drivers of the Initiative for Health and Vaccination that united the efforts of Parliamentary Health Commission, National Council for Integration on Ethnic and Integration Issues, Ministry of Health (MoH), Regional Health Inspectorates (regional structures of MoH), General practitioners. As a result, about 188 000 complementary measles vaccinations were administered with the assistance of the HMs who explained from door to door to parents the importance of child vaccinations.

The success of the initiative in 2010 lead to a second campaign in 2011, when NNHM was again invited by the MoH to cooperate with the Regional Health Inspectorates in a national campaign for vaccination against poliomyelitis with about 8400 children who received vaccine.

Throughout the last 10 years the HMs participated in different projects of the Network and its partners – HMs were interviewers of people from the communities in several surveys on health and social status of Roma; HMs organized information gatherings on the topics of discrimination and helped victims to address the institutions in charge; HMs carried out meetings in the communities for addressing the issues of early marriages and domestic violence; HMs were trained to work with children on personal hygiene; annually, HMs support the work of the mobile units providing prophylactic check-ups for health uninsured people, with health information campaigns and organization of check-ups; HMs are partners of all institutions on the territory of their municipalities and take part in local initiatives focused on Roma communities. In some small municipalities, the HM is the only Roma working in the municipality – in this way, all kinds of issues concerning local Roma are addressed to him/ her.

Q8: In your opinion, what are the attitudes / beliefs of the Roma population towards vaccination? Do you think health mediators can help improve these attitudes / beliefs?

A: Many of the common concerns about vaccines in Roma populations echo those outside the community. In Bulgarian society the old-fashioned ideas that measles and rubella are diseases the child should just “pull through” still persist. In some cases healthy children are taken to meet infected ones because some still believe that the earlier the child “passes” through this, the better. In the Roma community these views are also present, plus the suspicion that vaccination could cause sterility. In general, the Roma community needs more health information about vaccines and how they work.

Roma parents are concerned that vaccination could make their child ill. They are not acquainted with the normal side-effects of vaccination such as redness etc; the GPs usually don’t have the time to explain to every parent what is normal and what is not and sometimes parents get concerned if the child feels discomfort. This is also a task of the HM – to explain all this – why this vaccine is important, why it should be administered within a given period, what are the possible complications if the child gets ill from a vaccine-preventable disease.

In the first months of their work, newly-trained health mediators have several important tasks, one of which is to establish contacts with all health and social institutions representatives working on the territory of the municipality. One of these important contacts is with the general practitioners that work with Roma patients. The GPs prepare lists with non-vaccinated children and give them to the HM. The HM finds the parents of these children and explains to them why it is important to vaccinate their children.

After explanation from GP or HM, Roma parents usually agree that vaccination is needed and important but still some of them don’t take their children to the GP’s consulting room. We have observed better results when the vaccination campaigns are organised in the field, within the community, at a place where Roma people could gather without leaving their locality. The other successful method is the health-informational work of a HM in the community and, in certain cases, having the HM accompany some of the children to the GP.

Q9: Can all these explain why vaccination coverage is lower among Roma population compared to national averages?

A: In addition to certain beliefs of fears among Roma, children may also miss out vaccinations either because their parents do not have health insurance and have fewer contacts with health services as a result, or because the children are not registered with GPs. There are families that travel to work abroad together with their children and sometimes the immunization status of these travelling children is also not clear, so the HMs are not able to find them when the time for immunization comes. Another problem is the unwillingness of some GPs to collaborate with HMs; there are many cases of GPs that report immunizations that haven't been administered in practice – because the parents didn't show up or weren't found or because they missed an appointment.

Q10: How can this issue be addressed, in your opinion?

A: Our experience shows that, in the neighbourhoods where HMs work well with GPs, the cases of epidemic outbreaks are less or missing. For example, the GP working since 2005 in the town of Straldza together with the local HM has in her list 3000 patients (1000 of them children). She recently reported 1500 prophylactic check-ups carried out for one year; 900 immunizations (including on the field); and for the period 2012-2016 – 180 immunizations for HPV (recommended vaccination in Bulgarian Immunization Schedule covered by the state for girls of age 12 and 13 years).

In addition, control over the GP practices should be tightened – not only for GPs that report immunizations that weren't actually administered but also for GPs that refuse to follow the obligatory Immunization Schedule and the recommended immunizations (HPV and rotavirus).

Q11: Was there an evaluation of the project conducted? If yes, what were the results?

A: Until now, no external evaluation of the National Health Mediation Program was conducted. NNHM makes efforts to carry out internal monitoring and evaluation of the work of the HMs. At the end of 2016, the Ministry of Health approved unified reporting forms for HMs developed by NNHM and made it obligatory for all HMs in the country to fill in the forms – the quantitative results gathered from these reports are summarized by the NNHM team on a 6-month basis. In addition, since the beginning of 2017 the team of the Network carries out monitoring visits to HMs and municipalities – however this internal monitoring is not able to cover all working HMs in a short time, since all monitoring activities are financed only by projects implemented by NNHM and not by operative funding.

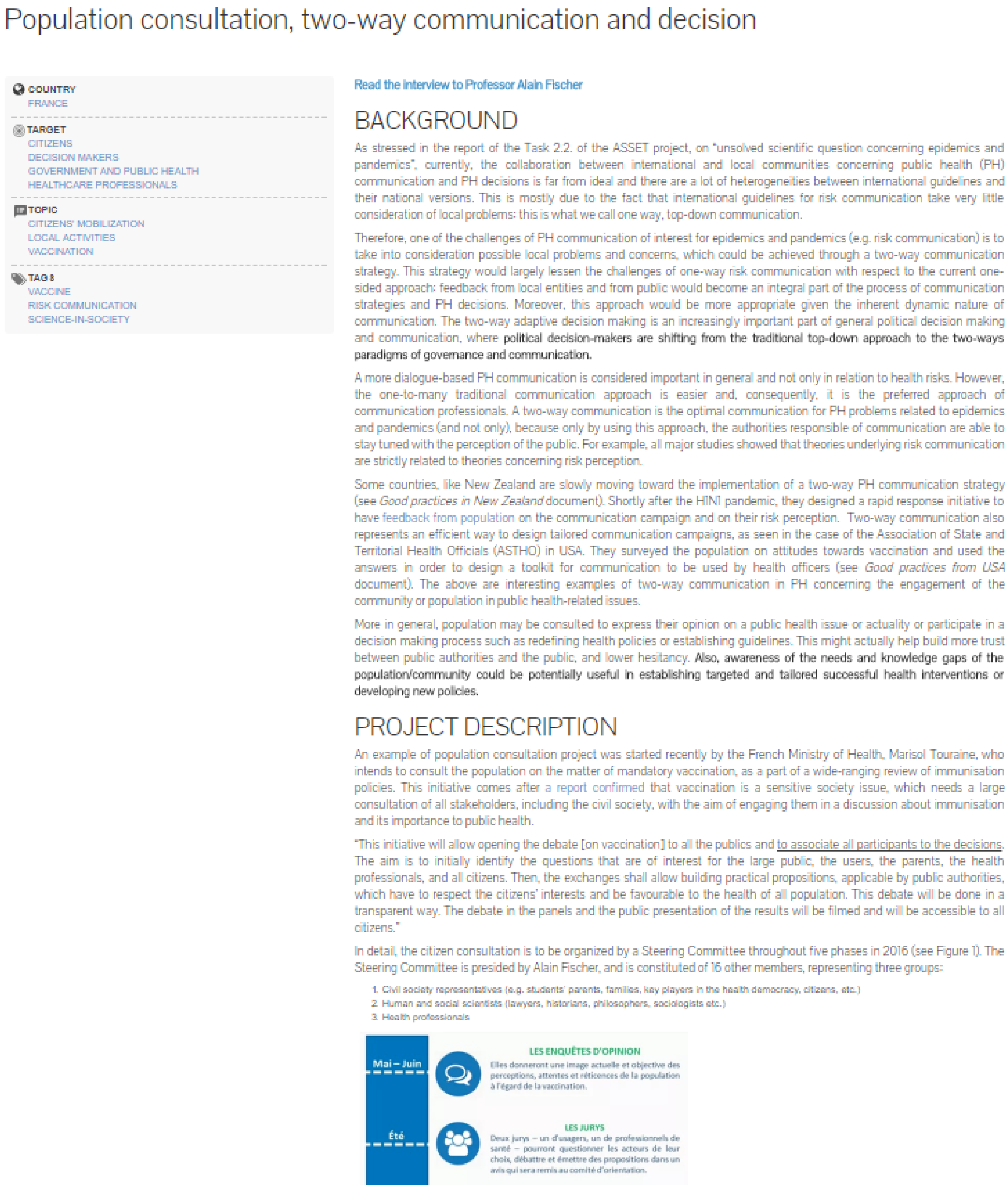
Q12: Do you think your project could be implemented in other regions / countries / communities? Has this already been the case?

A: Before being introduced in Bulgaria, the health mediation model was already functioning in other European countries, the closest being Romania. Although the models differ from country to country, the health/ cultural mediation is known also in Spain, Holland, France, Finland, Italy, Belgium, Slovakia, Serbia, FYROM, and Moldova. With some of these countries we have ongoing exchange of experience and good practices, we have also partnerships with several organizations working for the sustainability of national mediation programs.

Q13: Please feel free to add any other comments you might have.

A: You could watch the video clip "Profession Health Mediator"; the short film "To Build a Bridge" presenting the work of Bulgarian HMs; the video clip Roma Health Mediators-Bulgaria. Also, you could visit our website www.zdravenmediator.net

5.3 Population consultation, two-way communication and decision in France



Population consultation, two-way communication and decision

COUNTRY
FRANCE

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
CITIZENS' MOBILIZATION
LOCAL ACTIVITIES
VACCINATION

TAGS
VACCINE
RISK COMMUNICATION
SCIENCE-IN-SOCIETY

Read the interview to Professor Alain Fischer

BACKGROUND

As stressed in the report of the Task 2.2. of the ASSET project, on "unsolved scientific question concerning epidemics and pandemics", currently, the collaboration between international and local communities concerning public health (PH) communication and PH decisions is far from ideal and there are a lot of heterogeneities between international guidelines and their national versions. This is mostly due to the fact that international guidelines for risk communication take very little consideration of local problems: this is what we call one way, top-down communication.

Therefore, one of the challenges of PH communication of interest for epidemics and pandemics (e.g. risk communication) is to take into consideration possible local problems and concerns, which could be achieved through a two-way communication strategy. This strategy would largely lessen the challenges of one-way risk communication with respect to the current one-sided approach: feedback from local entities and from public would become an integral part of the process of communication strategies and PH decisions. Moreover, this approach would be more appropriate given the inherent dynamic nature of communication. The two-way adaptive decision making is an increasingly important part of general political decision making and communication, where political decision-makers are shifting from the traditional top-down approach to the two-ways paradigms of governance and communication.

A more dialogue-based PH communication is considered important in general and not only in relation to health risks. However, the one-to-many traditional communication approach is easier and, consequently, it is the preferred approach of communication professionals. A two-way communication is the optimal communication for PH problems related to epidemics and pandemics (and not only), because only by using this approach, the authorities responsible of communication are able to stay tuned with the perception of the public. For example, all major studies showed that theories underlying risk communication are strictly related to theories concerning risk perception.

Some countries, like New Zealand are slowly moving toward the implementation of a two-way PH communication strategy (see *Good practices in New Zealand* document). Shortly after the H1N1 pandemic, they designed a rapid response initiative to have feedback from population on the communication campaign and on their risk perception. Two-way communication also represents an efficient way to design tailored communication campaigns, as seen in the case of the Association of State and Territorial Health Officials (ASTHO) in USA. They surveyed the population on attitudes towards vaccination and used the answers in order to design a toolkit for communication to be used by health officers (see *Good practices from USA* document). The above are interesting examples of two-way communication in PH concerning the engagement of the community or population in public health-related issues.

More in general, population may be consulted to express their opinion on a public health issue or actuality or participate in a decision making process such as redefining health policies or establishing guidelines. This might actually help build more trust between public authorities and the public, and lower hesitancy. Also, awareness of the needs and knowledge gaps of the population/community could be potentially useful in establishing targeted and tailored successful health interventions or developing new policies.

PROJECT DESCRIPTION

An example of population consultation project was started recently by the French Ministry of Health, Marisol Touraine, who intends to consult the population on the matter of mandatory vaccination, as a part of a wide-ranging review of immunisation policies. This initiative comes after a report confirmed that vaccination is a sensitive society issue, which needs a large consultation of all stakeholders, including the civil society, with the aim of engaging them in a discussion about immunisation and its importance to public health.

"This initiative will allow opening the debate [on vaccination] to all the publics and to associate all participants to the decisions. The aim is to initially identify the questions that are of interest for the large public, the users, the parents, the health professionals, and all citizens. Then, the exchanges shall allow building practical propositions, applicable by public authorities, which have to respect the citizens' interests and be favourable to the health of all population. This debate will be done in a transparent way. The debate in the panels and the public presentation of the results will be filmed and will be accessible to all citizens."

In detail, the citizen consultation is to be organized by a Steering Committee throughout five phases in 2016 (see Figure 1). The Steering Committee is presided by Alain Fischer, and is constituted of 16 other members, representing three groups:

1. Civil society representatives (e.g. students' parents, families, key players in the health democracy, citizens, etc.)
2. Human and social scientists (lawyers, historians, philosophers, sociologists etc.)
3. Health professionals

LES ENQUÊTES D'OPINION

Elles donneront une image actuelle et objective des perceptions, attentes et réticences de la population à l'égard de la vaccination.

LES JURYS

Deux jurys – un d'usagers, un de professionnels de santé – pourront questionner les acteurs de leur choix, débattre et émettre des propositions dans un avis qui sera remis au comité d'orientation.

5.3.1 Factsheet

GOOD PRACTICE NAME: 2 WAY COMMUNICATION AND DECISION ON VACCINATION

MAIN THEME: VACCINATION, 2-WAY COMMUNICATION AND DECISION MAKING IN PUBLIC HEALTH

SPECIFIC SUB-THEME: Consulting population on vaccination; increasing awareness of vaccinations

COUNTRY: FRANCE

KEYWORDS: VACCINATION, 2-WAY COMMUNICATION,DECISION, DEBATE, PH DECISION-MAKERS, POLITICAL DECISION-MAKERS, HEALTH POLICIES, IMMUNIZATION POLICY,COMMUNICATION, INFORMATION, AWARENESS, CITIZEN, HEALTH PROFFESSIONALS

START DATE: January 2016

END DATE: End of 2016

KEY OBJECTIVES:

- Identify questions of interest regarding attitudes towards vaccination of the population.
- Organize a national public debate on these major questions.
- Formulate practical propositions to integrate in the renewed vaccination policy, using conclusions of the debates

WEBSITE: http://concertation-vaccination.fr/

CONTACT PERSONS (email): Alain FISCHER – President of the Steering Committee; Claude RAMBAUD – Vice-President of the Steering Committee; contact page on the website (http://concertation-vaccination.fr/contact/)

PROJECT INITIATORS: The Ministry Of Health and Social Affairs

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: NATIONAL

5.3.2 Background/context

As stressed in the report of the Task 2.2. of the ASSET project, on “unsolved scientific question concerning epidemics and pandemics”, currently, the collaboration between international and local communities concerning public health (PH) communication and PH decisions is far from ideal and there are a lot of heterogeneities between international guidelines and their national versions. This is mostly due to the fact that international guidelines for risk communication take very little consideration of local problems: this is what we call one way, top-down communication.

Therefore, one of the challenges of PH communication of interest for epidemics and pandemics (e.g. risk communication) is to take into consideration possible local problems and concerns, which could be achieved through a two-way communication strategy.

This strategy would largely lessen the challenges of one-way risk communication with respect to the current one-sided approach: feedback from local entities and from public would become an integral part of the process of communication strategies and PH decisions.

Moreover, this approach would be more appropriate given the inherent dynamic nature of communication.

The two-way adaptive decision making is an increasingly important part of general political decision making and communication, where **political decision-makers are shifting from the traditional top-down approach to the two-ways paradigms of governance and communication.**

A more dialogue-based PH communication is considered important in general and not only in relation to health risks. However, the one-to-many traditional communication approach is easier and, consequently, it is the preferred approach of communication professionals.

A two-way communication is the optimal communication for PH problems related to epidemics and pandemics (and not only), because only by using this approach, the authorities responsible of communication are able to stay tuned with the perception of the public. For example, all major studies showed that theories underlying risk communication are strictly related to theories concerning risk perception.

Some countries, like New Zealand are slowly moving toward the implementation of a two-way PH communication strategy (see *Good practices in New Zealand* document). Shortly after the H1N1 pandemic, they designed a rapid response initiative to have feedback from population on the communication campaign and on their risk perception[1]. Two-way communication also represents an efficient way to design tailored communication campaigns, as seen in the case of the Association of State and Territorial Health Officials (ASTHO) in USA. They surveyed the population on attitudes towards vaccination and used the answers in order to design a toolkit for communication to be used by health officers (see *Good practices from USA* document

The above are interesting examples of two-way communication in PH concerning the engagement of the community or population in public health-related issues.

More in general, population may be consulted to express their opinion on a public health issue or actuality or participate in a decision making process such as redefining health policies or establishing guidelines. This might

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[1] Gray L, MacDonald C, Mackie B, Paton D, Johnston D, Baker MG. Community responses to communication campaigns for influenza A (H1N1): a focus group study. BMC Public Health. 2012

actually help build more trust between public authorities and the public, and lower hesitancy. **Also, awareness of the needs and knowledge gaps of the population/community could be potentially useful in establishing targeted and tailored successful health interventions or developing new policies.**

5.3.3 Project description

An example of population consultation project was started recently by the French Ministry of Health, Marisol Touraine, who intends to consult the population on the matter of mandatory vaccination, as a part of a wide-ranging review of immunisation policies. This initiative comes after a report confirmed that vaccination is a sensitive society issue[2], which needs a large consultation of all stakeholders, including the civil society, with the aim of engaging them in a discussion about immunisation and its importance to public health.

"This initiative will allow opening the debate [on vaccination] to all the publics and to associate all participants to the decisions.

The aim is to initially identify the questions that are of interest for the large public, the users, the parents, the health professionals, and all citizens. Then, the exchanges shall allow building practical propositions, applicable by public authorities, which have to respect the citizens' interests and be favourable to the health of all population.

This debate will be done in a transparent way. The debate in the panels and the public presentation of the results will be filmed and will be accessible to all citizens."

In detail, the citizen consultation is to be organized by a Steering Committee throughout five phases in 2016 (see Figure below). The Steering Committee is presided by Alain Fischer, and is constituted of 16 other members, representing three groups:

1. Civil society representatives (e.g. students' parents, families, key players in the health democracy, citizens, etc.)
2. Human and social scientists (lawyers, historians, philosophers, sociologists etc.)
3. Health professionals

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[2] Hurel S, Rapport sur la politique vaccinale, Jan 2016

Figure - Timeline of the project

Mai – Juin

LES ENQUÊTES D'OPINION

Elles donneront une image actuelle et objective des perceptions, attentes et réticences de la population à l'égard de la vaccination.

Été

LES JURYS

Deux jurys – un d'usagers, un de professionnels de santé – pourront questionner les acteurs de leur choix, débattre et émettre des propositions dans un avis qui sera remis au comité d'orientation.

Septembre

LA PLATEFORME WEB

Chaque citoyen pourra publier son opinion et réagir aux avis des jurys. Les contributions seront analysées afin qu'aucune question ne soit écartée du débat.

Automne

LA JOURNÉE PUBLIQUE DE CLÔTURE

Une journée publique de restitution et de mise en débats des avis et contributions en ligne sera organisée. Elle sera filmée et ouverte à tous les Français.

Fin 2016

LA REMISE DU RAPPORT FINAL

Le comité fera la synthèse des propositions et remettra à la ministre un rapport qui permettra de contribuer à la rénovation de la politique vaccinale en France.

concertation-vaccination.fr

The first phase of the project consists in surveying the public opinion regarding the attitudes, expectations and reasons of reluctance or hesitancy to vaccination among the French population.

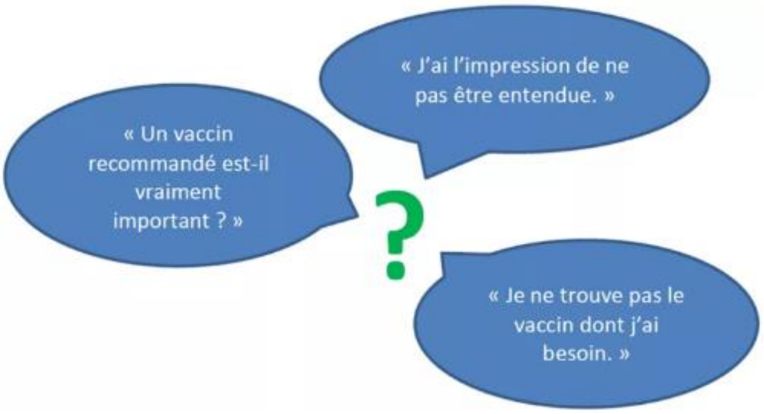
Then, two panels will be constituted, containing each 20 to 30 people: one composed of citizens and one composed of health professionals. These panels will represent different professions and categories such as region, age, social status etc.

Contributions will be collected on a national scale from citizens, health professionals, associations and institutions on a web-based platform, resulting in the collection of all major questions (see Figure below), opinions, expectations and perceptions around vaccination that the population has, such as:

- Should the difference between mandatory and recommended vaccines be kept?

- What is the perception of the individual benefit/risk?
- What is the acceptance of risk related to vaccination/non-vaccination etc.?

Figure - Examples of potential questions that population might have



The second phase consists of a national public debate discussing the panels' opinions and the contents of the citizen contributions.

Finally, during the third phase, conclusions on the evolution of the vaccination policy will be formulated, based on all contributions, from the panels' debate and also from the population. These conclusions will afterwards be transformed in a series of proposals allowing the renewal of the vaccination policy in France.

The project has also a newsletter[3], where interested individuals can register, and be kept in touch with the news related to the project and its advancement.

This project, if implemented according its original plan currently available online[4], would be an emblematic example of a good practice in the two-way communication and decision.

5.3.4 Status of the project

The French citizen consultation project is finished**.** The final report and conclusions of the project were published on the 30th of November 2016[5].

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[3] http://concertation-vaccination.fr/contact/newsletter/
[4] http://concertation-vaccination.fr/
[5] http://concertation-vaccination.fr/la-restitution/

5.3.5 Results

From September 14 to October 14, 2016, the Steering Committee opened an online participatory space where contributions were collected on a national scale: 10,435 contributions from Internet users were gathered. Answers to the open question, placed first, consisted in several critical contributions to vaccination, expressing mainly rejection of the mandatory nature of vaccines, a lack of confidence in pharmaceutical laboratories and a lack of confidence in the medical profession. Answers for the two targeted questions consisted in more positive contributions: the positive side of mandatory immunization is above all associated with childhood immunization.

Moreover, based on the two opinion surveys (Phase 1), the work of the two juries - one of citizens, one of health professionals (Phase 2) -, and the contributions received in the online participatory space, the committee issued a final report of recommendations for actions.

In this final report, the committee recommends the persistent mobilization of public authorities in order to implement a plan of action promoting the policy of prevention of infections through vaccination. This plan should include a series of measures essential to restore population’s trust in vaccination such as:

- **Transparency of information and experts:**
  All persons involved in the process of vaccines marketing or in the debates and decisions related to vaccination should fill in a public “conflict of interest” statement in order to insure transparency. Also, scientific information concerning vaccination (e.g. benefits, risks, adverse effects, etc.) should be transparently communicated, even if they are controversial. Public access to raw data from vaccination clinical trials together with transparent communication could allow a better understanding and interpretation.

- **Dissemination of validated information from a single known referral site :**
  Public authorities should set up a **unique** website, gathering all vaccination-related information and with a participative space. It should be accessible, on one hand to the general public, and on the other hand to health professionals. Dissemination of information from a unique source could increase population’s trust.

  This website should be able to respond in real time to current issues and should propose spaces for exchanging and dialogue with Internet users (questions, forums, question-answers, personalized information), thus being mindful of the population. It should also include a specific entry for health professionals.

- **Initial and maintained training of health professionals**
  Both juries and opinion polls have confirmed that healthcare professionals and especially general practitioners are in the front line to inform their patients about vaccination. Their education on vaccination appeared insufficient, with more than half of them feeling uncomfortable talking to patients because of the lack of training (initial and continuous) and sufficient information. The same is valid for students who also feel they are under-trained. It is recommended to increase teaching time on vaccination during the initial training of medical students, by creating a specific teaching unit that includes training in motivational interviewing. This teaching time should also be reinforced for pharmacy students, midwives and nursing students.

- **Involvement of the school**

School has two complementary missions in terms of public health: to follow-up on the health of the students and to provide them with health education. Vaccination should be included in the health education curriculum and young adults should be made aware of vaccination in their universities. School could also become the place of vaccination, if the lack of doctors and nurses in schools is palliated through reinforcement of the workforce but also through allowing people outside the institution (for example, nurses and physicians) to vaccinate.

- **Develop the communication**

  Communicating on a large scale would help showing the commitment of public authorities, who should reinstate the speech on vaccination, now essentially left to the vaccine-opponents. The committee insists on the necessity to develop an ambitious system of communication for the general public, coupled with a device for informing professionals.

  To be effective, the communication system should be designed over time, combining strong media moments (national promotional campaigns in major media) and widely disseminated educational tools (brochures, posters, professional intervention tools) in particularly through regional health agencies (ARS). Specific actions aimed at countering rumours and informing users via social networks should be intensified and could rely on journalists.

- **Facilitation of vaccination practice & improved follow-up through the generalization of the electronic health record**

  Recommendations from juries suggest that enlargement of the staff authorized to vaccinate could facilitate the vaccination practice; for instance, volunteering pharmacists should be allowed to inject vaccines against seasonal influenza, as long as the practice is regulated.

  One of the obstacles to vaccination raised by the citizen consultation is that people have often a lack of knowledge regarding their own vaccination status, as well as the vaccination schedule to respect. Thus, the loss of the immunization record, forgetfulness of the vaccines received and the lack of knowledge of the recall dates are all factors contributing to the reduction in immunization coverage. According to the two panels, the main recommendation in this area is to allow the patient to become an actor of his health by giving him access to the necessary information about his vaccination status. The professional jury also notes that doctors can be led to "over-vaccinate" patients due to lack of information available on their past vaccinations. The establishment of an electronic vaccination record would allow a reliable monitoring of vaccination.

- **Development of research programs covering different aspects of vaccination - from biology to the humanities and social sciences**

  Vaccination represents a major (though not unique) strategy for the prevention of infectious diseases. The research is very active, evidenced by the recent development of new vaccines such as vaccines against meningococcus B or dengue. However, many issues remain unresolved and many serious infectious diseases are still not covered by vaccination. According to this citizen consultation, different aspects of vaccinations should be actively researched:

    - New vaccines,
    - Additives,

  - Different vaccine efficiency depending on co-morbidities present e.g. diabetes, cancer, auto-immune diseases etc.,
  - Ways of administrations,
  - Personal response to vaccination,
  - Detection of rare adverse effects,
  - Research in human and social sciences

- **Expanding the mandatory nature of vaccination, with specific conditions**
  In the long term, through all the above-mentioned actions and their impact, it should be possible to lift the compulsory status and to base the vaccination on the understanding of its benefits for everyone, at individual and collective level. This requires regular assessments of perceptions of vaccination among the population and health professionals. In the meantime, the Committee recommends the temporary extension of the immunization obligation with an exemption clause until the conditions are met for lifting the obligation. This solution appears to be the best compromise between public health imperatives and public acceptability. The possibility of eventually lifting the obligations implies the immediate implementation of all the recommendations necessary to restore confidence in vaccination.

  In order for such an important decision to be understood and accepted, full coverage or reimbursement of vaccines cost by compulsory health insurance schemes must be ensured. The cost of such a measure is estimated at 110 to 120 million € / year. This measure alone cannot be considered sufficient to increase immunization coverage but would be a strong signal of the authorities' desire to promote vaccine prevention.

5.3.6 Interview with Alain Fischer

Name of the Best Practice: French Citizen Consultation on Vaccination

Name of the person of contact: ***Professor Alain Fischer*** *(info@concertation-vaccination.fr), doctor, professor of paediatric immunology, director of the Institute Imagine, holder of the chair of Experimental Medicine of the Collège de France and President of the Steering Committee for the Citizen Consultation initiative.*

Q1: How did this initiative start? What were the needs it addressed?

This initiative took place in early 2016, when the French Ministry of Health, Marisol Touraine, became aware of an existing problem regarding vaccination in previous years in France. Namely, vaccination rates were lower than expected, and for some vaccines, they were even declining. Moreover, there were lots of people claiming that vaccination was not useful, useless or maybe dangerous in the media or on the internet.

Following these kind of claims, the idea was to organize a citizen consultation in order to confront lay people with the science of vaccination, and discuss with experts, which could lead to common recommendations for actions to be completed by the Ministry of Health in this context. The hope was that having this citizen consultation may help the general population better accept the reasons for which vaccines should be performed.

Q2: Can you describe in which ways civil society was included in your project?

Civil society was included by definition, since citizen consultation means that lay people were selected to form a group (between 20-25 people), rather representative of the overall French population in terms of age, sex, socio-economic status, or geographical location. Since they did not know much about vaccination, during three days, they received intensive courses on vaccination, and over the next three days, they decided who they would like to listen to and to whom they wanted to discuss vaccination-related issues of vaccination before preparing a report. In parallel, a second consultation was performed, that of health care professionals who were not experts in vaccination. The same procedure was applied, a small group of people was selected, which had the same training, hearings and did the same reporting as the group of lay people mentioned earlier.

Their reports were discussed with us, us meaning a group of people including scientists on different topics as well as representatives of the civil society who eventually, evaluated the final report.

Q3: Why do you think it was important to include civil society in your project?

As I mentioned it earlier, there was some kind of misunderstanding in terms of communication between health care authorities and some part of the population as well as a small fraction of health care providers, so the idea was if the civil society (represented by these small groups of people) participated in formulating these recommendations would help the general population accept them more easily , as they are not only coming from the health care authorities or the government, but also emanating from lay people. This may not be sufficient but it may help the population better accept given policy.

Q4: How will civil society’s contributions be integrated afterwards?

These contributions were already integrated: after both groups finished their reports, we had a common meeting with them, during which we discussed more in details their proposals. Of course, the two groups were not always in agreement, but we listened to both sides’ proposals. This discussion led to an “almost consensus” on what should be done and afterwards, based on this discussion and their reports, the final report was conducted. Therefore, civil society’s involvement was very strong.

Q5: What was the conclusion of the citizen consultation regarding mandatory vaccination?

First of all, everyone concluded that vaccination is key in healthcare and prevention of infectious diseases and that vaccination altogether should be promoted in the society. The second conclusion was that everything should be done to promote vaccination, including teaching information communication to make access to vaccines easier and several other similar actions (see final report for more details). The final conclusion was that the vaccines that are required before the age of 2 (small children) should be made mandatory for at least a period of time, mainly because the trust of the population in vaccination was not high enough to allow vaccines to be optional.

Q6: Is the recent law project on making eleven vaccines mandatory a direct application of this initiative?

Following the final report, it took some time actually, also because of the change of government, but the actual Ministry of Health has launched a bill to make eleven vaccines mandatory that were so far only recommended for young children. This is definitely a direct application of the conclusions of the citizen consultation.

Q7: What were some of the challenges overcome during the project and some of the lessons learned?

One of the challenges we were confronted to during our work were fake news and similar conspiracy theories against vaccines; it is very hard to fight against these, because these rumours and fake news are very well disseminated in the media. In order to fight against these rumours, vaccination should be put in a better perspective in terms of its risks and benefits, leading to the population and more particularly, hesitant people’ better understanding of why is it so important to have a majority of the population that is vaccinated.

Q8: Was there an evaluation of the project conducted? If yes, what were the results?

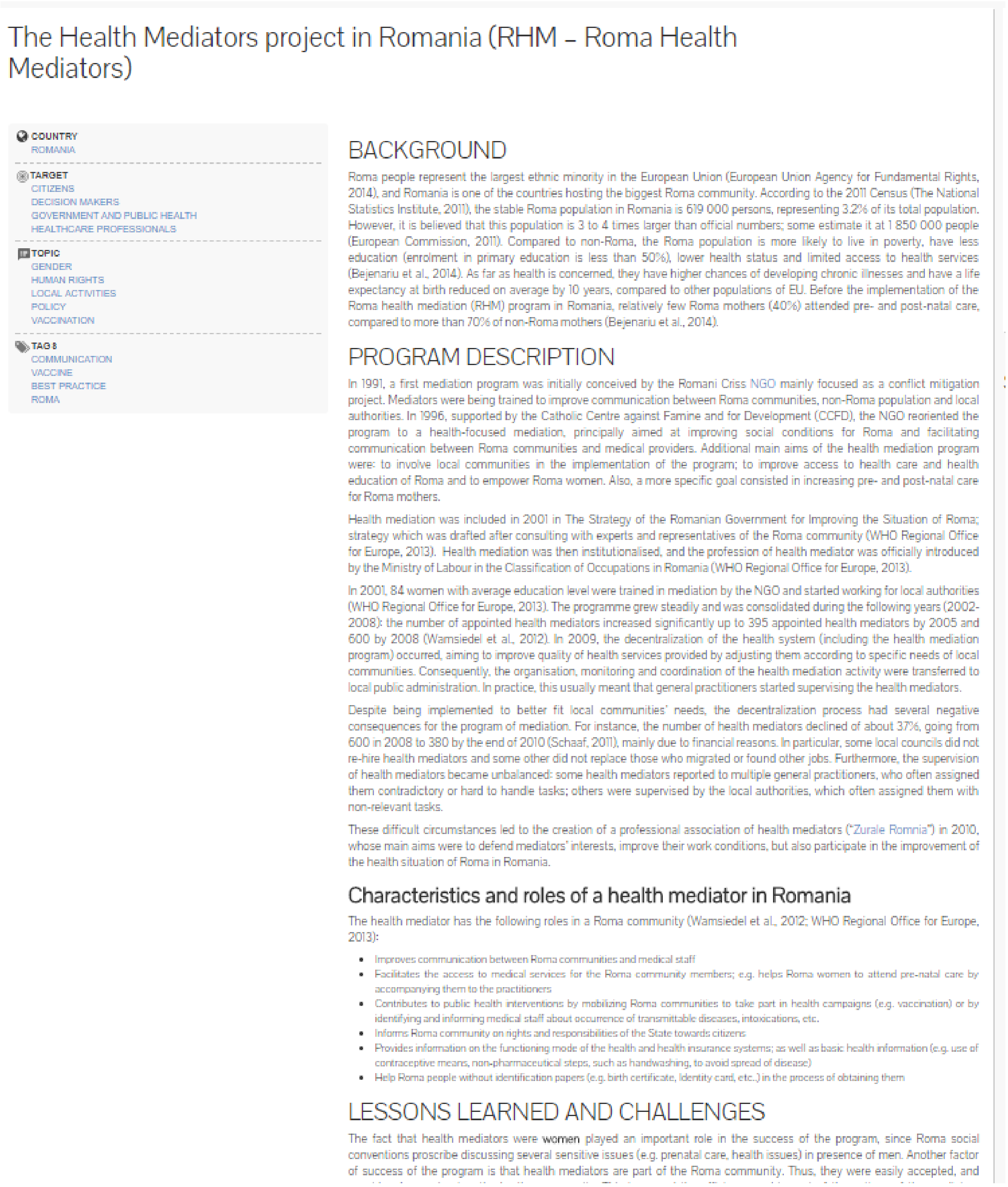
It is still too early for an evaluation of all of this. Since vaccines will be made compulsory starting the 1st of January, 2018, I think that an evaluation would be feasible 6 months later. Obviously, the conclusions were assessed by many people including, of course, the health authorities, but it is not strictly per se an evaluation.

Q9: Do you think your project could be implemented in other regions / countries / communities? Has this already been the case?

In terms of vaccination, I am not so sure. Some other countries are facing the same kind of problems, for instance Italy. In their case, no such procedure was implemented, but the Ministry reached the same conclusion: to make compulsory vaccines in children. It is possible, otherwise, that the work we have done here in France was used in Italy, because the problem was similar.

So why not implement it elsewhere? Unfortunately, there are other countries in the world facing such difficulties with vaccination that could proceed with this kind of citizen consultations, knowing that, as you know, in other fields of healthcare or even fields outside healthcare, these procedures are used quite frequently, starting with Denmark, approximately 20 years ago. Therefore, it is a procedure occasionally used by countries facing social issues.

5.4 The Health Mediators project in Romania (RHM – Roma Health Mediators)



The Health Mediators project in Romania (RHM – Roma Health Mediators)

COUNTRY
ROMANIA

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
GENDER
HUMAN RIGHTS
LOCAL ACTIVITIES
POLICY
VACCINATION

TAGS
COMMUNICATION
VACCINE
BEST PRACTICE
ROMA

BACKGROUND

Roma people represent the largest ethnic minority in the European Union (European Union Agency for Fundamental Rights, 2014), and Romania is one of the countries hosting the biggest Roma community. According to the 2011 Census (The National Statistics Institute, 2011), the stable Roma population in Romania is 619 000 persons, representing 3.2% of its total population. However, it is believed that this population is 3 to 4 times larger than official numbers; some estimate it at 1 850 000 people (European Commission, 2011). Compared to non-Roma, the Roma population is more likely to live in poverty, have less education (enrolment in primary education is less than 50%), lower health status and limited access to health services (Bejenariu et al., 2014). As far as health is concerned, they have higher chances of developing chronic illnesses and have a life expectancy at birth reduced on average by 10 years, compared to other populations of EU. Before the implementation of the Roma health mediation (RHM) program in Romania, relatively few Roma mothers (40%) attended pre- and post-natal care, compared to more than 70% of non-Roma mothers (Bejenariu et al., 2014).

PROGRAM DESCRIPTION

In 1991, a first mediation program was initially conceived by the Romani Criss NGO mainly focused as a conflict mitigation project. Mediators were being trained to improve communication between Roma communities, non-Roma population and local authorities. In 1996, supported by the Catholic Centre against Famine and for Development (CCFD), the NGO reoriented the program to a health-focused mediation, principally aimed at improving social conditions for Roma and facilitating communication between Roma communities and medical providers. Additional main aims of the health mediation program were: to involve local communities in the implementation of the program; to improve access to health care and health education of Roma and to empower Roma women. Also, a more specific goal consisted in increasing pre- and post-natal care for Roma mothers.

Health mediation was included in 2001 in The Strategy of the Romanian Government for Improving the Situation of Roma; strategy which was drafted after consulting with experts and representatives of the Roma community (WHO Regional Office for Europe, 2013). Health mediation was then institutionalised, and the profession of health mediator was officially introduced by the Ministry of Labour in the Classification of Occupations in Romania (WHO Regional Office for Europe, 2013).

In 2001, 84 women with average education level were trained in mediation by the NGO and started working for local authorities (WHO Regional Office for Europe, 2013). The programme grew steadily and was consolidated during the following years (2002-2008): the number of appointed health mediators increased significantly up to 395 appointed health mediators by 2005 and 600 by 2008 (Wamsiedel et al., 2012). In 2009, the decentralization of the health system (including the health mediation program) occurred, aiming to improve quality of health services provided by adjusting them according to specific needs of local communities. Consequently, the organisation, monitoring and coordination of the health mediation activity were transferred to local public administration. In practice, this usually meant that general practitioners started supervising the health mediators.

Despite being implemented to better fit local communities' needs, the decentralization process had several negative consequences for the program of mediation. For instance, the number of health mediators declined of about 37%, going from 600 in 2008 to 380 by the end of 2010 (Schaaf, 2011), mainly due to financial reasons. In particular, some local councils did not re-hire health mediators and some other did not replace those who migrated or found other jobs. Furthermore, the supervision of health mediators became unbalanced: some health mediators reported to multiple general practitioners, who often assigned them contradictory or hard to handle tasks; others were supervised by the local authorities, which often assigned them with non-relevant tasks.

These difficult circumstances led to the creation of a professional association of health mediators ("Zurale Romnia") in 2010, whose main aims were to defend mediators' interests, improve their work conditions, but also participate in the improvement of the health situation of Roma in Romania.

Characteristics and roles of a health mediator in Romania

The health mediator has the following roles in a Roma community (Wamsiedel et al., 2012; WHO Regional Office for Europe, 2013):

- Improves communication between Roma communities and medical staff
- Facilitates the access to medical services for the Roma community members; e.g. helps Roma women to attend pre-natal care by accompanying them to the practitioners
- Contributes to public health interventions by mobilizing Roma communities to take part in health campaigns (e.g. vaccination) or by identifying and informing medical staff about occurence of transmittable diseases, intoxications, etc.
- Informs Roma community on rights and responsibilities of the State towards citizens
- Provides information on the functioning mode of the health and health insurance systems; as well as basic health information (e.g. use of contraceptive means, non-pharmaceutical steps, such as handwashing, to avoid spread of disease)
- Help Roma people without identification papers (e.g. birth certificate, Identity card, etc.) in the process of obtaining them

LESSONS LEARNED AND CHALLENGES

The fact that health mediators were women played an important role in the success of the program, since Roma social conventions proscribe discussing several sensitive issues (e.g. prenatal care, health issues) in presence of men. Another factor of success of the program is that health mediators are part of the Roma community. Thus, they were easily accepted, and

5.4.1 Factsheet

GOOD PRACTICE NAME: HEALTH MEDIATION

MAIN THEME: VACCINATION AND PREVENTION

SPECIFIC Sub-THEME: Health mediation; increasing awareness of vaccinations in hard to reach populations, targeting Public Health Actions and Risk communication to vulnerable and hard to reach communities

COUNTRY: ROMANIA

KEYWORDS: HEALTH MEDIATION, VACCINATION, VULNERABLE GROUPS, HARD TO REACH POPULATION, ETHNIC MINORITIES, ROMA POPULATION, PREVENTION, COMMUNICATION, AWARENESS, BEHAVIOR CHANGE, ADAPTING PUBLIC HEALTH MESSAGES/ACTIONS

START DATE: 1996

END DATE: Still running

KEY OBJECTIVES:

- Involve local communities in the programme implementation → civic mobilisation
- Facilitate communication between Roma and medical communities
- Improve access to health care and health education of Roma
- Empower Roma women

WEBSITE: http://www.romanicriss.org/en/

CONTACT PERSONS (email):

Marian Mandache - Executive Director marian@romanicriss.org

Brici Carmen - Project assistant in the Health department carmen@romanicriss.org

Or office@romanicriss.org

PROJECT INITIATORS: national and local health system initiative

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: BOTH

5.4.2 Background/context

Roma people represent the largest ethnic minority in the European Union (European Union Agency for Fundamental Rights, 2014), and Romania is one of the countries hosting the biggest Roma community. According to the 2011 Census (The National Statistics Institute, 2011), the stable Roma population in Romania was 619 000 persons, representing 3.2% of its total population. However, it is believed that this population is 3 to 4 times larger than official numbers; some estimate it at 1 850 000 people (European Commission, 2011).

Compared to non-Roma, the Roma population is more likely to live in poverty, have less education (enrolment in primary education is less than 50%), lower health status and limited access to health services (Bejenariu et al., 2014).

As far as health is concerned, they have higher chances of developing chronic illnesses and have a life expectancy at birth reduced on average by 10 years, compared to other populations of EU.

Before the implementation of the Roma health mediation (RHM) program in Romania, relatively few Roma mothers (40%) attended pre- and post-natal care, compared to more than 70% of non-Roma mothers (Bejenariu et al., 2014).

5.4.3 Program description

In 1991, a first mediation program was initially conceived by the Romani Criss NGO[6] mainly focused as a conflict mitigation project. Mediators were being trained to improve communication between Roma communities, non-Roma population and local authorities.

In 1996, supported by the Catholic Centre against Famine and for Development (CCFD), the NGO reoriented the program to a health-focused mediation, principally aimed at improving social conditions for Roma and facilitating communication between Roma communities and medical providers.

Additional main aims of the health mediation program were: to involve local communities in the implementation of the program; to improve access to health care and health education of Roma and to empower Roma women. Also, a more specific goal consisted in increasing pre- and post-natal care for Roma mothers.

Health mediation was included in 2001 in The Strategy of the Romanian Government for Improving the Situation of Roma; strategy which was drafted after consulting with experts and representatives of the Roma community (WHO Regional Office for Europe, 2013). Health mediation was then institutionalised, and the profession of health mediator was officially introduced by the Ministry of Labour in the Classification of Occupations in Romania (WHO Regional Office for Europe, 2013).

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[6] http://www.romanicriss.org/

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Despite being implemented to better fit local communities' needs, the decentralization process had several negative consequences for the program of mediation. For instance, the number of health mediators declined of about 37%, going from 600 in 2008 to 380 by the end of 2010 (Schaaf, 2011), mainly due to financial reasons. In particular, some local councils did not re-hire health mediators and some other did not replace those who migrated or found other jobs.

Furthermore, the supervision of health mediators became unbalanced: some health mediators reported to multiple general practitioners, who often assigned them contradictory or hard to handle tasks; others were supervised by the local authorities, which often assigned them with non-relevant tasks.

These difficult circumstances led to the creation of a professional association of health mediators ("Zurale Romnia"[7]) in 2010, whose main aims were to defend mediators' interests, improve their work conditions, but also participate in the improvement of the health situation of Roma in Romania.

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- Provides information on the functioning mode of the health and health insurance systems; as well as basic health information (e.g. use of contraceptive means, non-pharmaceutical steps, such as handwashing, to avoid spread of disease)

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[7] https://romanonromasocialcohesion.wordpress.com/partners-2/zurale-romania/

- Help Roma people without identification papers (e.g. birth certificate, Identity card, etc..) in the process of obtaining them

8.4.4 Lessons learned and challenges

The fact that health mediators were **women** played an important role in the success of the program, since Roma social conventions proscribe discussing several sensitive issues (e.g. prenatal care, health issues) in presence of men. Another factor of success of the program is that health mediators are part of the Roma community. Thus, they were easily accepted, and considered more trustworthy by the community. This increased the efficiency and impact of the actions of the mediators (Bejenariu et al., 2014).

Bejenariu and co-workers (2014) evaluated the effects of the health mediation program on prenatal care and child health in Roma communities, using data from the Vital Statistics Natality and Mortality files, and from the Roma health mediators' registry. They concluded that the program significantly increased attendance of Roma women to prenatal care appointments. However, no improvements were observed in low birth weight or premature delivery, but the number of stillbirths and infant deaths decreased slightly following the implementation of the program.

Health mediators raised awareness on subjects such as family planning, healthy lifestyle, vaccination and hygiene and might have contributed to a change in Roma's health-related behaviour (WHO Regional Office for Europe, 2013). As a matter of fact, many of health mediators' duties concern the area of infectious diseases, such as reporting the number of identified cases of tuberculosis, promoting health vaccination campaigns and inciting Roma populations to participate, as well as assisting the medical personnel during vaccination campaigns.

However, there is very few data concerning translation of these behaviours into tangible actions: going more often to the doctor, vaccinate their children, etc.

Concerning vaccination rates, data is scarce; it is not known how much the RHM program improved vaccination rates among Roma communities (Schaaf, 2011). This may be due to the fact that unvaccinated Roma people are also often undocumented.

Multiple evaluations of the program considered it a success and a model for future implementation of health mediation programs, as a close collaboration between NGOs and government (WHO Regional Office for Europe, 2013), with high geographical and demographical coverage. It was estimated that 660 000 Roma have been served by a HM at some point; this represents between one third and one fourth of the Roma population in Romania.

However, they also pointed out some major faults and avenues for improvement, and identified several challenges encountered during the implementation process, such as insufficient training, poor work conditions (low salaries, fixed-term contracts, job insecurity, etc.) and the decentralisation which impacted the activity of health mediation.

The following recommendations not only indicate ways to improve the current health mediation program, but should also be considered when designing and implementing a new health mediation program (Schaaf, 2011; WHO Regional Office for Europe, 2013):

- **Involve the target group in all phases of the project**
- Better organize the supervision of health mediators, by defining more clearly who takes the responsibility of supervision and to whom health mediators have to report
- Provide adequate funding and consequently ensure job security of health mediators
- Provide high quality training to health mediators, but also sensitise the medical body involved to existing cultural differences

5.4.5 Status of the project

The project of Health Mediators in Romania is still ongoing. It has been implemented in other countries with important Roma communities across Europe:

- **France**: there is a national health mediation program that started to be implemented during the period (2010-2012)[8]. National coordination of the project is ensured by the Association pour l'Accueil des Voyageurs (ASAV) (*see best practice document on Health Mediators in France*).
- **Serbia:** The health mediation programme was initiated in 2008 by the Serbian Ministry of Health in cooperation with OSCE and the European Agency for Reconstruction[9].
- **Bulgaria:** the Health mediator model was launched in 2001 by the team of "Ethnic Minorities Health Problems Foundation" (*see best practice document on Health Mediators in Bulgaria*)
- **Macedonia:** the health mediation program was launched by the Macedonian NGO HERA[10] (Health Education and Research Association) in 2009-2010, with support from the Open Society Foundations.
- **Slovakia**: The Roma Health mediation program started in 2005, as part of a larger program that was funded by PHARE.
- **Ukraine:** The Roma Health mediation program started in 2010, coordinated by the Ukrainian NGO Chiricli[11] in collaboration with the Ministry of Labour and Social Policy and other non-governmental bodies.

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[10] http://hera.org.mk/
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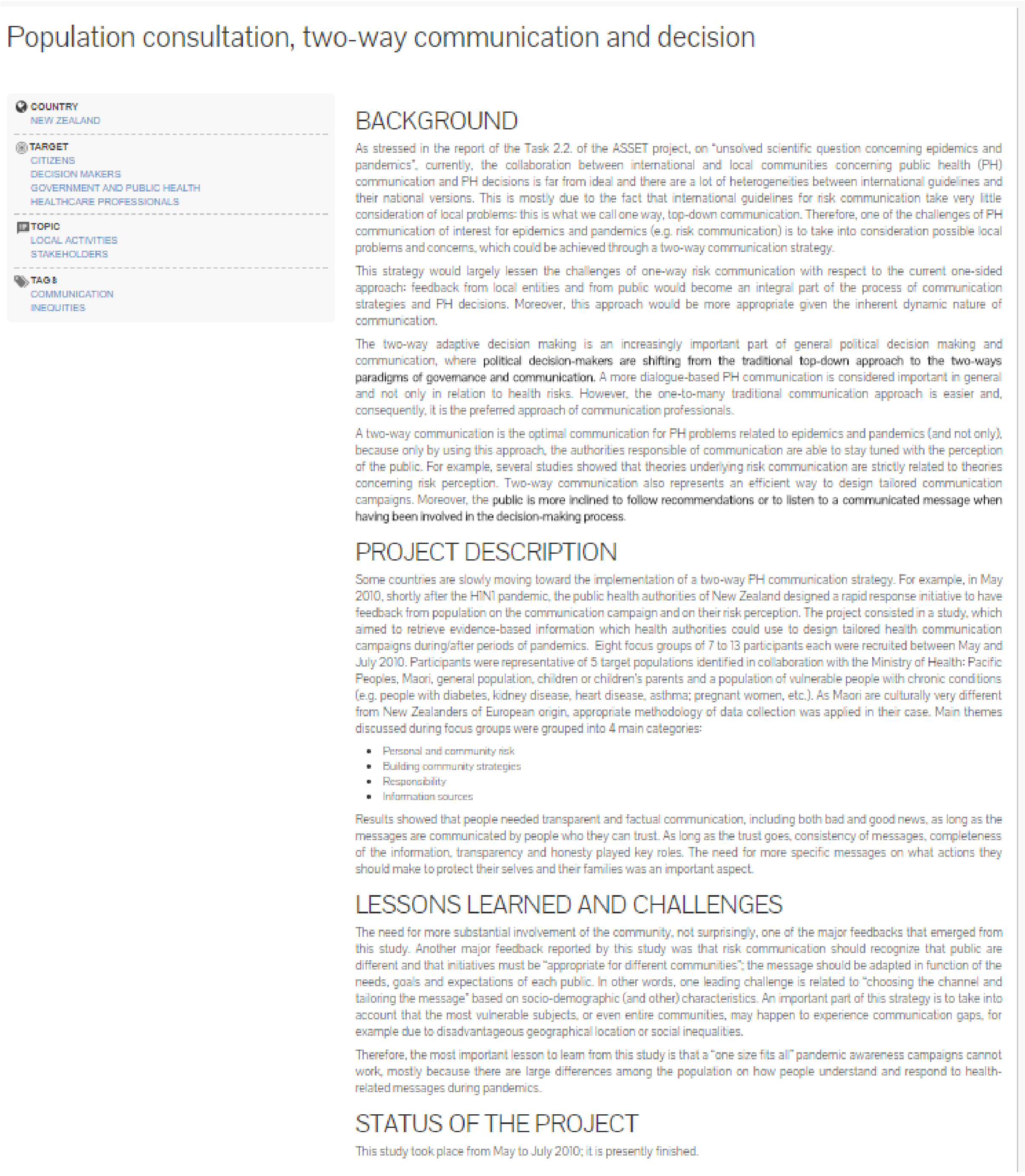
5.5 Population consultation, two-way communication and decision in New Zealand



Population consultation, two-way communication and decision

COUNTRY
NEW ZEALAND

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
LOCAL ACTIVITIES
STAKEHOLDERS

TAGS
COMMUNICATION
INEQUITIES

BACKGROUND

As stressed in the report of the Task 2.2. of the ASSET project, on "unsolved scientific question concerning epidemics and pandemics", currently, the collaboration between international and local communities concerning public health (PH) communication and PH decisions is far from ideal and there are a lot of heterogeneities between international guidelines and their national versions. This is mostly due to the fact that international guidelines for risk communication take very little consideration of local problems: this is what we call one way, top-down communication. Therefore, one of the challenges of PH communication of interest for epidemics and pandemics (e.g. risk communication) is to take into consideration possible local problems and concerns, which could be achieved through a two-way communication strategy.

This strategy would largely lessen the challenges of one-way risk communication with respect to the current one-sided approach: feedback from local entities and from public would become an integral part of the process of communication strategies and PH decisions. Moreover, this approach would be more appropriate given the inherent dynamic nature of communication.

The two-way adaptive decision making is an increasingly important part of general political decision making and communication, where **political decision-makers are shifting from the traditional top-down approach to the two-ways paradigms of governance and communication.** A more dialogue-based PH communication is considered important in general and not only in relation to health risks. However, the one-to-many traditional communication approach is easier and, consequently, it is the preferred approach of communication professionals.

A two-way communication is the optimal communication for PH problems related to epidemics and pandemics (and not only), because only by using this approach, the authorities responsible of communication are able to stay tuned with the perception of the public. For example, several studies showed that theories underlying risk communication are strictly related to theories concerning risk perception. Two-way communication also represents an efficient way to design tailored communication campaigns. Moreover, the **public is more inclined to follow recommendations or to listen to a communicated message when having been involved in the decision-making process.**

PROJECT DESCRIPTION

Some countries are slowly moving toward the implementation of a two-way PH communication strategy. For example, in May 2010, shortly after the H1N1 pandemic, the public health authorities of New Zealand designed a rapid response initiative to have feedback from population on the communication campaign and on their risk perception. The project consisted in a study, which aimed to retrieve evidence-based information which health authorities could use to design tailored health communication campaigns during/after periods of pandemics. Eight focus groups of 7 to 13 participants each were recruited between May and July 2010. Participants were representative of 5 target populations identified in collaboration with the Ministry of Health: Pacific Peoples, Maori, general population, children or children's parents and a population of vulnerable people with chronic conditions (e.g. people with diabetes, kidney disease, heart disease, asthma; pregnant women, etc.). As Maori are culturally very different from New Zealanders of European origin, appropriate methodology of data collection was applied in their case. Main themes discussed during focus groups were grouped into 4 main categories:

- Personal and community risk
- Building community strategies
- Responsibility
- Information sources

Results showed that people needed transparent and factual communication, including both bad and good news, as long as the messages are communicated by people who they can trust. As long as the trust goes, consistency of messages, completeness of the information, transparency and honesty played key roles. The need for more specific messages on what actions they should make to protect their selves and their families was an important aspect.

LESSONS LEARNED AND CHALLENGES

The need for more substantial involvement of the community, not surprisingly, one of the major feedbacks that emerged from this study. Another major feedback reported by this study was that risk communication should recognize that public are different and that initiatives must be "appropriate for different communities"; the message should be adapted in function of the needs, goals and expectations of each public. In other words, one leading challenge is related to "choosing the channel and tailoring the message" based on socio-demographic (and other) characteristics. An important part of this strategy is to take into account that the most vulnerable subjects, or even entire communities, may happen to experience communication gaps, for example due to disadvantageous geographical location or social inequalities.

Therefore, the most important lesson to learn from this study is that a "one size fits all" pandemic awareness campaigns cannot work, mostly because there are large differences among the population on how people understand and respond to health-related messages during pandemics.

STATUS OF THE PROJECT

This study took place from May to July 2010; it is presently finished.

5.5.1 Factsheet

GOOD PRACTICE NAME: 2-WAY COMMUNICATION AND DECISION ON VACCINATION

MAIN THEME: 2-WAY COMMUNICATION AND DECISION MAKING IN PUBLIC HEALTH

SPECIFIC SUB-THEME: Consulting population on risk communication campaign during epidemics

COUNTRY: New Zealand

KEYWORDS: 2-WAY COMMUNICATION, TAILORED COMMUNICATION, COMMUNICATION CAMPAIGN, MESSAGE, FOCUS GROUP, H1N1 EPIDEMIC, COMMUNITY, TRUST, FEEDBACK, PREPAREDNESS, RISK PERCEPTION, INFORMATION, AWARENESS, INFLUENCE SOURCE

START DATE: May 2010

END DATE: July 2010

KEY OBJECTIVE:

Provide health authorities with evidence-based practical information to guide the conception and delivery of key messages for H1N1 and other health campaigns

WEBSITE: - (study conducted at the Massey University, article published http://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-12-205)

CONTACT PERSONS (email): Lesley.gray@otago.ac.nz (corresponding author of published article describing the study)

PROJECT INITIATORS: Massey University, New Zealand

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: LOCAL

5.5.2 Project description

Some countries are slowly moving toward the implementation of a two-way PH communication strategy. For example, in May 2010, shortly after the H1N1 pandemic, the public health authorities of New Zealand designed a rapid response initiative to have feedback from the population on the communication campaign and on their risk perception[12]. The project consisted in a study, which aimed to retrieve evidence-based information which health authorities could use to design tailored health communication campaigns during/after periods of pandemics. Eight focus groups of 7 to 13 participants each were recruited between May and July 2010. Participants were representative of 5 target populations identified in collaboration with the Ministry of Health: Pacific Peoples, Maori, general population, children or children's parents and a population of vulnerable people with chronic conditions (e.g. people with diabetes, kidney disease, heart disease, asthma; pregnant women, etc.). As Maori are culturally very different from New Zealanders of European origin, appropriate methodology of data collection was applied in their case.

Main themes discussed during focus groups were grouped into 4 main categories:

- Personal and community risk
- Building community strategies
- Responsibility
- Information sources

Results showed that people needed transparent and factual communication, including both bad and good news, as long as the messages are communicated by people who they can trust. As long as the trust goes, consistency of messages, completeness of the information, transparency and honesty played key roles. The need for more specific messages on what actions they should make to protect their selves and their families was an important aspect.

5.5.3 Lessons learned and challenges

The need for more substantial involvement of the community, not surprisingly, one of the major feedbacks that emerged from this study. Another major feedback reported by this study was that risk communication should recognize that public are different and that initiatives must be "appropriate for different communities"; the message should be adapted in function of the needs, goals and expectations of each public. In other words, one leading challenge is related to "choosing the channel and tailoring the message" based on socio-demographic (and other) characteristics.

An important part of this strategy is to take into account that the most vulnerable subjects, or even entire communities, may happen to experience communication gaps, for example due to disadvantageous geographical location or social inequalities.

Therefore, the most important lesson to learn from this study is that a "one size fits all" pandemic awareness campaigns cannot work, mostly because there are large differences among the population on how people understand and respond to health-related messages during pandemics.

5.5.4 Status of the project

This study took place from May to July 2010; it is presently finished.

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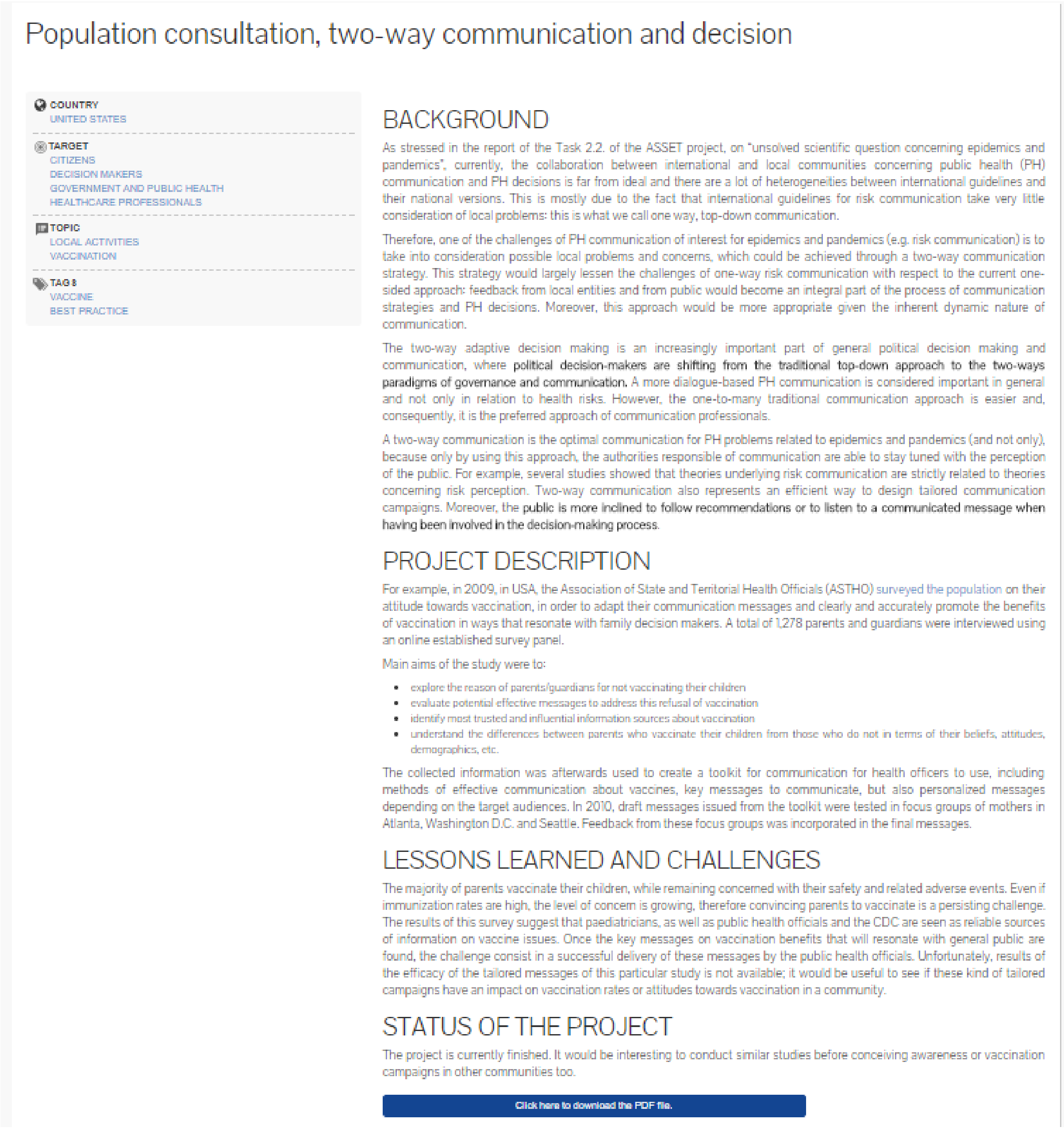
[12] Gray L, MacDonald C, Mackie B, Paton D, Johnston D, Baker MG. Community responses to communication campaigns for influenza A (H1N1): a focus group study. BMC Public Health. 2012

5.6 Population consultation, two-way communication and decision in USA



Population consultation, two-way communication and decision

COUNTRY
UNITED STATES

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
LOCAL ACTIVITIES
VACCINATION

TAGS
VACCINE
BEST PRACTICE

BACKGROUND

As stressed in the report of the Task 2.2. of the ASSET project, on "unsolved scientific question concerning epidemics and pandemics", currently, the collaboration between international and local communities concerning public health (PH) communication and PH decisions is far from ideal and there are a lot of heterogeneities between international guidelines and their national versions. This is mostly due to the fact that international guidelines for risk communication take very little consideration of local problems: this is what we call one way, top-down communication.

Therefore, one of the challenges of PH communication of interest for epidemics and pandemics (e.g. risk communication) is to take into consideration possible local problems and concerns, which could be achieved through a two-way communication strategy. This strategy would largely lessen the challenges of one-way risk communication with respect to the current one-sided approach: feedback from local entities and from public would become an integral part of the process of communication strategies and PH decisions. Moreover, this approach would be more appropriate given the inherent dynamic nature of communication.

The two-way adaptive decision making is an increasingly important part of general political decision making and communication, where political decision-makers are shifting from the traditional top-down approach to the two-ways paradigms of governance and communication. A more dialogue-based PH communication is considered important in general and not only in relation to health risks. However, the one-to-many traditional communication approach is easier and, consequently, it is the preferred approach of communication professionals.

A two-way communication is the optimal communication for PH problems related to epidemics and pandemics (and not only), because only by using this approach, the authorities responsible of communication are able to stay tuned with the perception of the public. For example, several studies showed that theories underlying risk communication are strictly related to theories concerning risk perception. Two-way communication also represents an efficient way to design tailored communication campaigns. Moreover, the public is more inclined to follow recommendations or to listen to a communicated message when having been involved in the decision-making process.

PROJECT DESCRIPTION

For example, in 2009, in USA, the Association of State and Territorial Health Officials (ASTHO) surveyed the population on their attitude towards vaccination, in order to adapt their communication messages and clearly and accurately promote the benefits of vaccination in ways that resonate with family decision makers. A total of 1,278 parents and guardians were interviewed using an online established survey panel.

Main aims of the study were to:

- explore the reason of parents/guardians for not vaccinating their children
- evaluate potential effective messages to address this refusal of vaccination
- identify most trusted and influential information sources about vaccination
- understand the differences between parents who vaccinate their children from those who do not in terms of their beliefs, attitudes, demographics, etc.

The collected information was afterwards used to create a toolkit for communication for health officers to use, including methods of effective communication about vaccines, key messages to communicate, but also personalized messages depending on the target audiences. In 2010, draft messages issued from the toolkit were tested in focus groups of mothers in Atlanta, Washington D.C. and Seattle. Feedback from these focus groups was incorporated in the final messages.

LESSONS LEARNED AND CHALLENGES

The majority of parents vaccinate their children, while remaining concerned with their safety and related adverse events. Even if immunization rates are high, the level of concern is growing, therefore convincing parents to vaccinate is a persisting challenge. The results of this survey suggest that paediatricians, as well as public health officials and the CDC are seen as reliable sources of information on vaccine issues. Once the key messages on vaccination benefits that will resonate with general public are found, the challenge consist in a successful delivery of these messages by the public health officials. Unfortunately, results of the efficacy of the tailored messages of this particular study is not available; it would be useful to see if these kind of tailored campaigns have an impact on vaccination rates or attitudes towards vaccination in a community.

STATUS OF THE PROJECT

The project is currently finished. It would be interesting to conduct similar studies before conceiving awareness or vaccination campaigns in other communities too.

5.6.1 Factsheet

GOOD PRACTICE NAME: 2-WAY COMMUNICATION AND DECISION ON VACCINATION

MAIN THEME: 2-WAY COMMUNICATION AND DECISION MAKING IN PUBLIC HEALTH

SPECIFIC Sub-THEME: Consulting population on vaccination; increasing awareness of vaccinations

COUNTRY: United States of America

KEYWORDS: CHILDHOOD VACCINATION, 2-WAY COMMUNICATION, TAILORED COMMUNICATION, COMMUNICATION CAMPAIGN, MESSAGE, SURVEY, PARENTS, PRO-VACCINATION, ANTI-VACCINATION, INFORMATION, AWARENESS, INFLUENCE SOURCE, PH DECISION-MAKERS

START DATE: August 2009

END DATE: August 2009 (2 weeks)

KEY OBJECTIVES:

- Investigate reasons parents and guardians have for not vaccinating their children
- Find the most effective messages for addressing this resistance
- Inform about vaccines that are the most trusted and influential
- Understand characteristics that distinguish parents who vaccinate from those who refuse, including their demographics, attitudes and beliefs, and responsiveness to messages for and against childhood vaccinations

WEBSITE: http://www.astho.org/Programs/Immunization/

CONTACT PERSONS (email):

Meredith Allen (mallen@astho.org) - Senior Director, Immunization and Infectious Disease

Yadashe Belay (ybelay@astho.org) - Administrative Coordinator, Immunization and Infectious Disease

Ericka McGowan (emcgowan@astho.org) - Director, Infectious Disease Preparedness

Chelsea Moultrie (cmoultrie@astho.org) - Administrative Coordinator, Community Health and Prevention

Elizabeth Ruebush (eruebush@astho.org) - Senior Analyst, Infectious Disease and Immunization Policy

Lisa Waddell (lwaddell@astho.org) - Chief Program Officer, Community Health and Prevention

PROJECT INITIATORS: ASTHO **(**national non-profit organization representing public health agencies in the United States, the U.S. Territories, and the District of Columbia, and over 100,000 public health professionals these agencies employ)

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: BOTH

5.6.2 Project description

For example, in 2009, in USA, the Association of State and Territorial Health Officials (ASTHO) surveyed the population on their attitude towards vaccination, in order to adapt their communication messages and clearly and accurately promote the benefits of vaccination in ways that resonate with family decision makers[13]. A total of 1,278 parents and guardians were interviewed using an online established survey panel.

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The collected information was afterwards used to create a toolkit for communication for health officers to use, including methods of effective communication about vaccines, key messages to communicate, but also personalized messages depending on the target audiences.

In 2010, draft messages issued from the toolkit were tested in focus groups of mothers in Atlanta, Washington D.C. and Seattle. Feedback from these focus groups was incorporated in the final messages.

8.6.3 Lessons learned and challenges

The majority of parents vaccinate their children, while remaining concerned with their safety and related adverse events. Even if immunization rates are high, the level of concern is growing, therefore convincing parents to vaccinate is a persisting challenge.

The results of this survey suggest that paediatricians, as well as public health officials and the CDC are seen as reliable sources of information on vaccine issues. Once the key messages on vaccination benefits that will resonate with general public are found, the challenge consist in a successful delivery of these messages by the public health officials.

Unfortunately, results of the efficacy of the tailored messages of this particular study is not available; it would be useful to see if these kind of tailored campaigns have an impact on vaccination rates or attitudes towards vaccination in a community.

8.6.4 Status of the project

The project is currently finished. It would be interesting to conduct similar studies before conceiving awareness or vaccination campaigns in other communities too.

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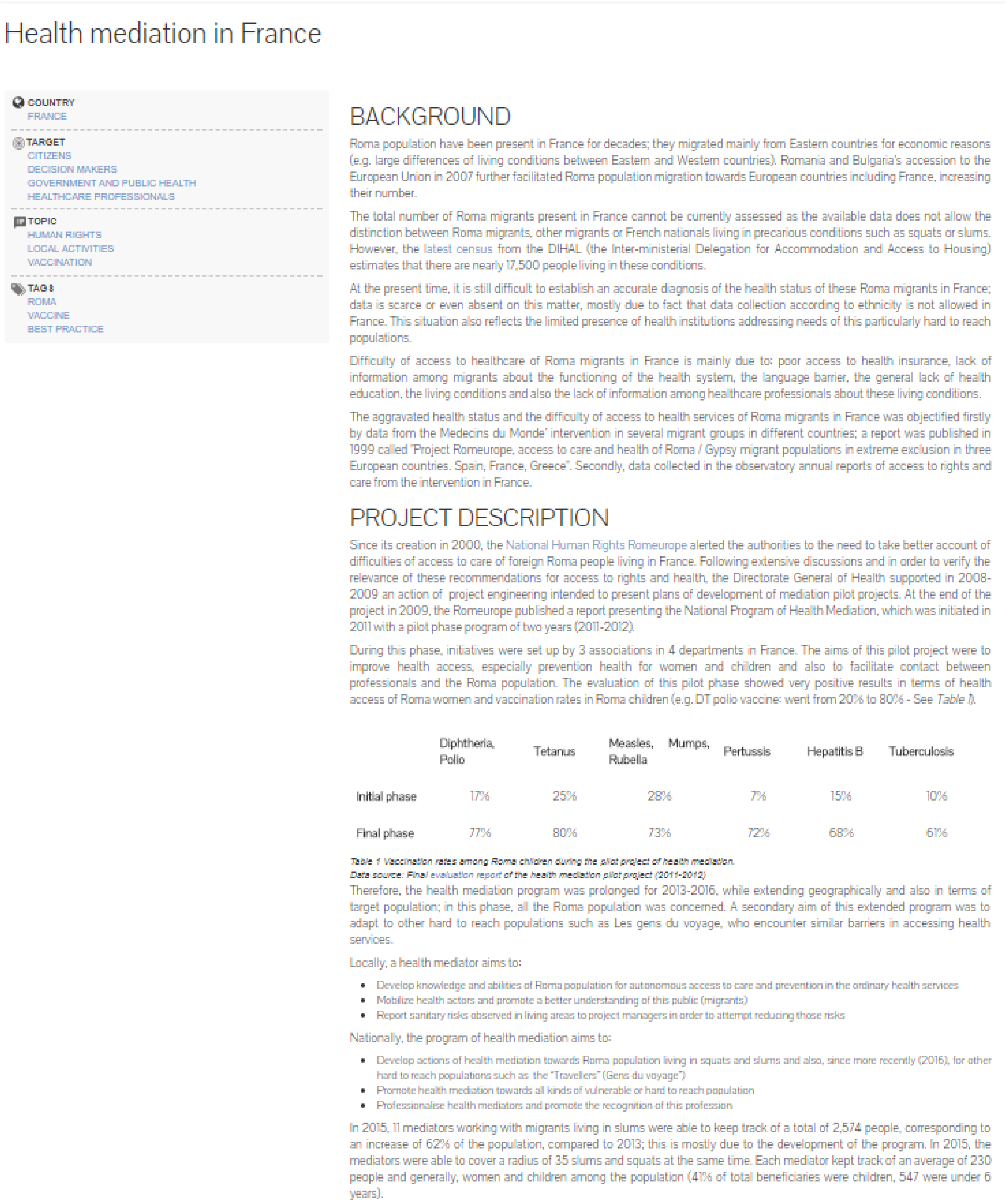
[13] http://www.astho.org/Programs/Immunization/Communicating-Effectively-About-Vaccines--Summary-of-a-Survey-of-U-S--Parents-and-Guardians/

5.7 Health mediation in France



Health mediation in France

COUNTRY
FRANCE

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
HUMAN RIGHTS
LOCAL ACTIVITIES
VACCINATION

TAGS
ROMA
VACCINE
BEST PRACTICE

BACKGROUND

Roma population have been present in France for decades; they migrated mainly from Eastern countries for economic reasons (e.g. large differences of living conditions between Eastern and Western countries). Romania and Bulgaria's accession to the European Union in 2007 further facilitated Roma population migration towards European countries including France, increasing their number.

The total number of Roma migrants present in France cannot be currently assessed as the available data does not allow the distinction between Roma migrants, other migrants or French nationals living in precarious conditions such as squats or slums. However, the latest census from the DIHAL (the Inter-ministerial Delegation for Accommodation and Access to Housing) estimates that there are nearly 17,500 people living in these conditions.

At the present time, it is still difficult to establish an accurate diagnosis of the health status of these Roma migrants in France; data is scarce or even absent on this matter, mostly due to fact that data collection according to ethnicity is not allowed in France. This situation also reflects the limited presence of health institutions addressing needs of this particularly hard to reach populations.

Difficulty of access to healthcare of Roma migrants in France is mainly due to: poor access to health insurance, lack of information among migrants about the functioning of the health system, the language barrier, the general lack of health education, the living conditions and also the lack of information among healthcare professionals about these living conditions.

The aggravated health status and the difficulty of access to health services of Roma migrants in France was objectified firstly by data from the Medecins du Monde' intervention in several migrant groups in different countries; a report was published in 1999 called "Project Romeurope, access to care and health of Roma / Gypsy migrant populations in extreme exclusion in three European countries. Spain, France, Greece". Secondly, data collected in the observatory annual reports of access to rights and care from the intervention in France.

PROJECT DESCRIPTION

Since its creation in 2000, the National Human Rights Romeurope alerted the authorities to the need to take better account of difficulties of access to care of foreign Roma people living in France. Following extensive discussions and in order to verify the relevance of these recommendations for access to rights and health, the Directorate General of Health supported in 2008-2009 an action of project engineering intended to present plans of development of mediation pilot projects. At the end of the project in 2009, the Romeurope published a report presenting the National Program of Health Mediation, which was initiated in 2011 with a pilot phase program of two years (2011-2012).

During this phase, initiatives were set up by 3 associations in 4 departments in France. The aims of this pilot project were to improve health access, especially prevention health for women and children and also to facilitate contact between professionals and the Roma population. The evaluation of this pilot phase showed very positive results in terms of health access of Roma women and vaccination rates in Roma children (e.g. DT polio vaccine: went from 20% to 80% - See *Table 1*).

	Diphtheria, Polio	Tetanus	Measles, Mumps, Rubella	Pertussis	Hepatitis B	Tuberculosis
Initial phase	17%	25%	28%	7%	15%	10%
Final phase	77%	80%	73%	72%	68%	61%

Table 1 Vaccination rates among Roma children during the pilot project of health mediation.
Data source: Final evaluation report of the health mediation pilot project (2011-2012)

Therefore, the health mediation program was prolonged for 2013-2016, while extending geographically and also in terms of target population; in this phase, all the Roma population was concerned. A secondary aim of this extended program was to adapt to other hard to reach populations such as Les gens du voyage, who encounter similar barriers in accessing health services.

Locally, a health mediator aims to:

- Develop knowledge and abilities of Roma population for autonomous access to care and prevention in the ordinary health services
- Mobilize health actors and promote a better understanding of this public (migrants)
- Report sanitary risks observed in living areas to project managers in order to attempt reducing those risks

Nationally, the program of health mediation aims to:

- Develop actions of health mediation towards Roma population living in squats and slums and also, since more recently (2016), for other hard to reach populations such as the "Travellers" (Gens du voyage")
- Promote health mediation towards all kinds of vulnerable or hard to reach population
- Professionalise health mediators and promote the recognition of this profession

In 2015, 11 mediators working with migrants living in slums were able to keep track of a total of 2,574 people, corresponding to an increase of 62% of the population, compared to 2013; this is mostly due to the development of the program. In 2015, the mediators were able to cover a radius of 35 slums and squats at the same time. Each mediator kept track of an average of 230 people and generally, women and children among the population (41% of total beneficiaries were children, 547 were under 6 years).

5.7.1 Factsheet

GOOD PRACTICE NAME: HEALTH MEDIATION

MAIN THEME: VACCINATION AND PREVENTION

SPECIFIC Sub-THEME: Health mediation; increasing awareness of vaccinations in hard to reach populations, targeting Public Health Actions and Risk communication to vulnerable and hard to reach communities

COUNTRY: FRANCE

KEYWORDS: HEALTH MEDIATION, VACCINATION, VULNERABLE GROUPS, HARD TO REACH POPULATION, ETHNIC MINORITIES, ROMA POPULATION, TRAVELLERS, PREVENTION, COMMUNICATION, AWARENESS, BEHAVIOR CHANGE, ADAPTING PUBLIC HEALTH MESSAGES/ACTIONS

START DATE: 2011

END DATE: Still running

KEY OBJECTIVES:

- Develop actions of health mediation towards Roma population living in squats and slums and also for other hard to reach populations such as the “Travellers” (Gens du voyage”)
- Promote health mediation towards all kinds of vulnerable or hard to reach population
- Professionalise health mediators and promote the recognition of this profession

WEBSITE: http://www.mediation-sanitaire.org/

CONTACT PERSONS (email):

Coordinator of the project at national level

Association pour l’Accueil des Voyageurs (ASAV)
E-mail : contact@asav92.fr

Or at http://www.mediation-sanitaire.org/contact/

PROJECT INITIATORS: local associations in 4 French departments

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: BOTH

5.7.2 Background

Roma population have been present in France for decades; they migrated mainly from Eastern countries for economic reasons (e.g. large differences of living conditions between Eastern and Western countries). Romania and Bulgaria’s accession to the European Union in 2007 further facilitated Roma population migration towards European countries including France, increasing their number.

The total number of Roma migrants present in France cannot be currently assessed as the available data does not allow the distinction between Roma migrants, other migrants or French nationals living in precarious conditions such as squats or slums. However, the latest census[14] from the DIHAL (the Inter-ministerial Delegation for Accommodation and Access to Housing) estimates that there are nearly 17,500 people living in these conditions.

At the present time, it is still difficult to establish an accurate diagnosis of the health status of these Roma migrants in France; data is scarce or even absent on this matter, mostly due to fact that data collection according to ethnicity is not allowed in France. This situation also reflects the limited presence of health institutions addressing needs of this particularly hard to reach populations.

Difficulty of access to healthcare of Roma migrants in France is mainly due to: poor access to health insurance, lack of information among migrants about the functioning of the health system, the language barrier, the general lack of health education, the living conditions and also the lack of information among healthcare professionals about these living conditions.

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[14] http://www.gouvernement.fr/un-meilleur-suivi-des-implantations-de-campements-et-bidonvilles-pour-une-politique-plus-efficace-5382

5.7.3 Project description

Since its creation in 2000, the National Human Rights Romeurope[15] alerted the authorities to the need to take better account of difficulties of access to care of foreign Roma people living in France.

Following extensive discussions and in order to verify the relevance of these recommendations for access to rights and health, the Directorate General of Health supported in 2008-2009 an action of project engineering intended to present plans of development of mediation pilot projects.

At the end of the project in 2009, the Romeurope published a report presenting the National Program of Health Mediation, which was initiated in 2011 with a pilot phase program of two years (2011-2012).

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Table- Vaccination rates among Roma children during the pilot project of health mediation

	Diphtheria, Polio	*Tetanus*	*Measles, Mumps, Rubella*	*Pertussis*	*Hepatitis B*	*Tuberculosis*
Initial phase	*17%*	*25%*	*28%*	*7%*	*15%*	*10%*
Final phase	*77%*	*80%*	*73%*	*72%*	*68%*	*61%*

Data source: Final evaluation report of the health mediation pilot project (2011-2012) [16]

Therefore, the health mediation program was prolonged for 2013-2016, while extending geographically and also in terms of target population; in this phase, all the Roma population was concerned. A secondary aim of this extended program was to adapt to other hard to reach populations such as Les gens du voyage, who encounter similar barriers in accessing health services.

Locally, a health mediator aims to:

- Develop knowledge and abilities of Roma population for autonomous access to care and prevention in the ordinary health services
- Mobilize health actors and promote a better understanding of this public (migrants)
- Report sanitary risks observed in living areas to project managers in order to attempt reducing those risks

Nationally, the program of health mediation aims to:

- Develop actions of health mediation towards Roma population living in squats and slums and also, since more recently (2016), for other hard to reach populations such as the “Travellers” (Gens du voyage”)

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[15] http://www.romeurope.org/spip.php?rubrique55

[16] Rapport final d’évaluation du programme experimental de médiation sanitaire 2011-2012 : http://www.mediation-sanitaire.org/wp-content/uploads/2012/08/rapport-final-d%C3%A9valuation-2011-2012-du-programme-exp%C3%A9rimental-de-m%C3%A9diation-sanitaire.pdf

- Promote health mediation towards all kinds of vulnerable or hard to reach population
- Professionalise health mediators and promote the recognition of this profession

In 2015, 11 mediators working with migrants living in slums were able to keep track of a total of 2,574 people, corresponding to an increase of 62% of the population, compared to 2013; this is mostly due to the development of the program. In 2015, the mediators were able to cover a radius of 35 slums and squats at the same time. Each mediator kept track of an average of 230 people and generally, women and children among the population (41% of total beneficiaries were children, 547 were under 6 years).

In 2016, 14 mediators were working for 12 local associations all over France. An interactive map of these 12 local projects is available here: http://www.mediation-sanitaire.org/les-acteurs/carte-interactive-des-12-projets-de-mediation-sanitaire-membres-du-programme/ .

A large part of health mediators' actions concern **infectious diseases, and their prevention** in Roma populations, either through behavioural prevention or through vaccination prevention.

Since the beginning of the program but mostly in 2015 and 2016, prevention tools have been co-created in collaboration with several health partners and also with the target populations; their aim was to be tailored to specific condition of health prevention in hard to reach populations[17]. These prevention tools included:

- The Pregnancy Book (Le carnet de grossesse Car'Mat'), a bilingual document aiming to familiarize pregnant women with all pregnancy-related challenges and necessary appointments
- The pedagogic movie "The mother and the Infant" ("La mère et l'infant"), a film for the awareness on subjects as on maternity, pregnancy care, contraception, sexually transmitted diseases and children vaccination
- Illustrative communication supports («Mon corps aussi » and « Le cycle de la femme et la grossesse »), conceived in 3 languages (Romanian, Hungarian, French), on topics such as sexual education or human body anatomy
- Movie on the hepatitis B prevention
- Education tool on tuberculosis (« Mythes ou réalités»), informing about tuberculosis transmission, symptoms, severity and treatment and aiming to change preconceived ideas on this disease
- The family card ("la carte famille"), a tool helping mediators explain the role of GPs and the health monitoring system in France

5.7.4 Lessons learned and challenges

Life in the slums and squats remains marked by strong insalubrity, insecurity, a relatively poor access to health facilities and living conditions unfavourable to health, in terms of access to water, electricity, sanitation and general welfare.

Territorial differences between conditions of reception of people living in slums/squats reflect the necessity of involvement of local communities and the need for health mediation promoters to put forward replicable practices for provision of sanitary facilities, access to water or servicing and relocation projects.

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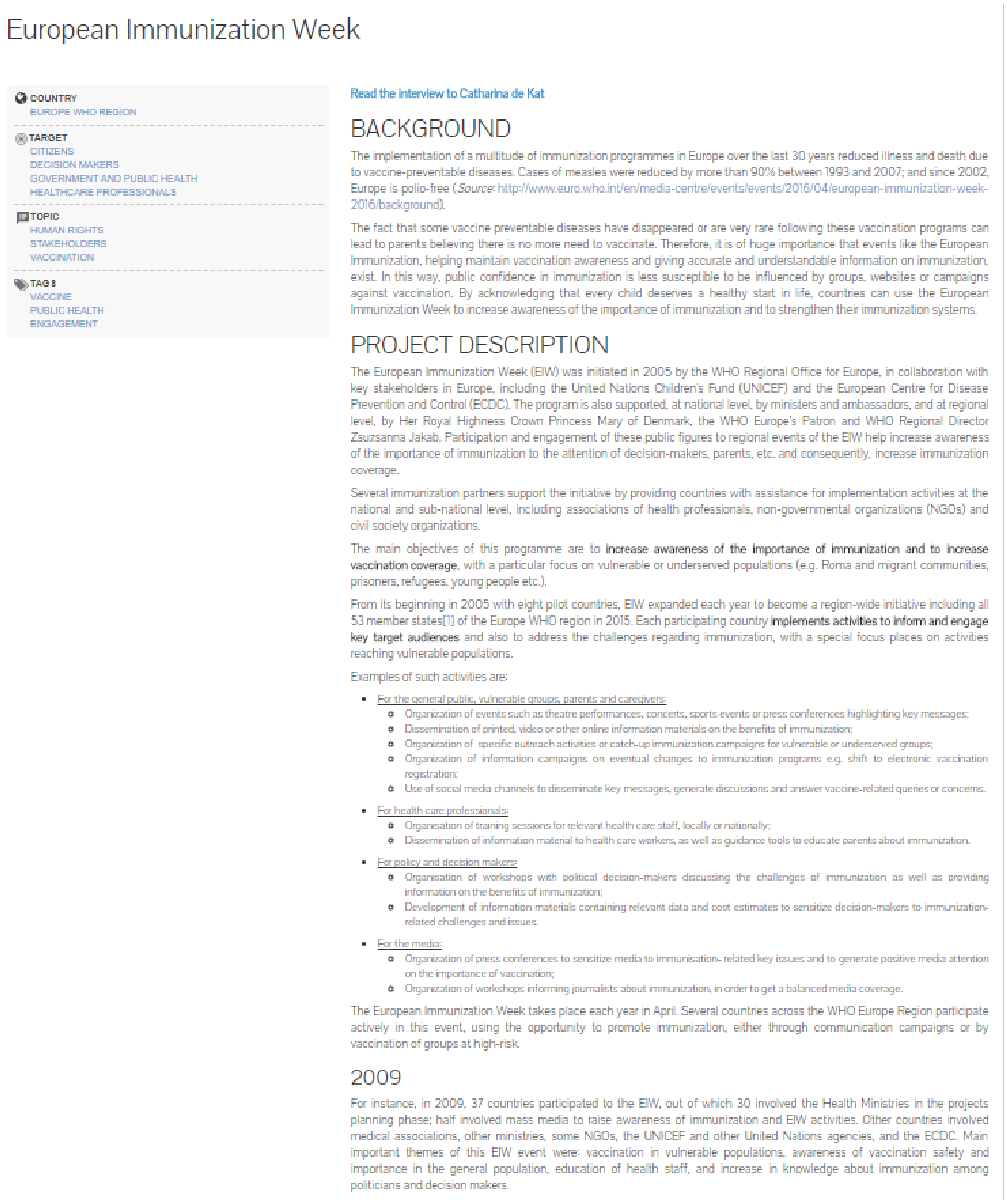
[17] http://www.mediation-sanitaire.org/les-outils/mallette/

If local health mediation initiatives put a lot of energy in access to housing, health coverage and response to health emergencies, **it is important to also attempt to lift barriers to health access in these populations on the long term.**

5.7.5 Status of the project

The project of health mediation in Roma populations in France is still ongoing. The final report evaluating the national mediation project is expected to be published at the end of 2016.

5.8 European Immunization Week



European Immunization Week

COUNTRY
EUROPE WHO REGION

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
HUMAN RIGHTS
STAKEHOLDERS
VACCINATION

TAGS
VACCINE
PUBLIC HEALTH
ENGAGEMENT

Read the interview to Catharina de Kat

BACKGROUND

The implementation of a multitude of immunization programmes in Europe over the last 30 years reduced illness and death due to vaccine-preventable diseases. Cases of measles were reduced by more than 90% between 1993 and 2007; and since 2002, Europe is polio-free (*Source*: http://www.euro.who.int/en/media-centre/events/events/2016/04/european-immunization-week-2016/background).

The fact that some vaccine preventable diseases have disappeared or are very rare following these vaccination programs can lead to parents believing there is no more need to vaccinate. Therefore, it is of huge importance that events like the European Immunization, helping maintain vaccination awareness and giving accurate and understandable information on immunization, exist. In this way, public confidence in immunization is less susceptible to be influenced by groups, websites or campaigns against vaccination. By acknowledging that every child deserves a healthy start in life, countries can use the European Immunization Week to increase awareness of the importance of immunization and to strengthen their immunization systems.

PROJECT DESCRIPTION

The European Immunization Week (EIW) was initiated in 2005 by the WHO Regional Office for Europe, in collaboration with key stakeholders in Europe, including the United Nations Children's Fund (UNICEF) and the European Centre for Disease Prevention and Control (ECDC). The program is also supported, at national level, by ministers and ambassadors, and at regional level, by Her Royal Highness Crown Princess Mary of Denmark, the WHO Europe's Patron and WHO Regional Director Zsuzsanna Jakab. Participation and engagement of these public figures to regional events of the EIW help increase awareness of the importance of immunization to the attention of decision-makers, parents, etc. and consequently, increase immunization coverage.

Several immunization partners support the initiative by providing countries with assistance for implementation activities at the national and sub-national level, including associations of health professionals, non-governmental organizations (NGOs) and civil society organizations.

The main objectives of this programme are to **increase awareness of the importance of immunization and to increase vaccination coverage**, with a particular focus on vulnerable or underserved populations (e.g. Roma and migrant communities, prisoners, refugees, young people etc.).

From its beginning in 2005 with eight pilot countries, EIW expanded each year to become a region-wide initiative including all 53 member states[1] of the Europe WHO region in 2015. Each participating country **implements activities to inform and engage key target audiences** and also to address the challenges regarding immunization, with a special focus places on activities reaching vulnerable populations.

Examples of such activities are:

- For the general public, vulnerable groups, parents and caregivers:
    - Organization of events such as theatre performances, concerts, sports events or press conferences highlighting key messages;
    - Dissemination of printed, video or other online information materials on the benefits of immunization;
    - Organization of specific outreach activities or catch-up immunization campaigns for vulnerable or underserved groups;
    - Organization of information campaigns on eventual changes to immunization programs e.g. shift to electronic vaccination registration;
    - Use of social media channels to disseminate key messages, generate discussions and answer vaccine-related queries or concerns.
- For health care professionals:
    - Organisation of training sessions for relevant health care staff, locally or nationally;
    - Dissemination of information material to health care workers, as well as guidance tools to educate parents about immunization.
- For policy and decision makers:
    - Organisation of workshops with political decision-makers discussing the challenges of immunization as well as providing information on the benefits of immunization;
    - Development of information materials containing relevant data and cost estimates to sensitize decision-makers to immunization-related challenges and issues.
- For the media:
    - Organization of press conferences to sensitize media to immunisation- related key issues and to generate positive media attention on the importance of vaccination;
    - Organization of workshops informing journalists about immunization, in order to get a balanced media coverage.

The European Immunization Week takes place each year in April. Several countries across the WHO Europe Region participate actively in this event, using the opportunity to promote immunization, either through communication campaigns or by vaccination of groups at high-risk.

2009

For instance, in 2009, 37 countries participated to the EIW, out of which 30 involved the Health Ministries in the projects planning phase; half involved mass media to raise awareness of immunization and EIW activities. Other countries involved medical associations, other ministries, some NGOs, the UNICEF and other United Nations agencies, and the ECDC. Main important themes of this EIW event were: vaccination in vulnerable populations, awareness of vaccination safety and importance in the general population, education of health staff, and increase in knowledge about immunization among politicians and decision makers.

5.8.1 Factsheet

GOOD PRACTICE NAME: European Immunization Week

MAIN THEME: Vaccination; immunization coverage

SPECIFIC Sub-THEME: Increasing awareness of the importance of immunization and to increase vaccination coverage

COUNTRY: EUROPE WHO Region (53 countries – Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Malta, Monaco, Montenegro, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, The former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine, United Kingdom of Great Britain and Northern Ireland, Uzbekistan)

KEYWORDS: VACCINATION, IMMUNIZATION, COVERAGE, AWARENESS, INFORMATION, COMMUNICATION, VULNERABLE GROUPS, CITIZENS, CIVIL SOCIETY, GOVERNMENT, POLITICAL DECISION-MAKERS, PH DECISION MAKERS,

START DATE: April 2005

END DATE: Still ongoing

KEY OBJECTIVE: To raise awareness of the importance of immunization and to increase vaccination coverage, with a special focus on vulnerable groups

WEBSITE: http://www.euro.who.int/en/health-topics/disease-prevention/vaccines-and-immunization/european-immunization-week

CONTACT PERSONS (email):

Robb Butler, Programme Manager
Vaccine-preventable Diseases and Immunization
Email: butlerr@who.int

Cristiana Salvi
Communications Officer
Email: salvic@who.int

PROJECT INITIATORS: WHO Europe

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: implemented at the level of the WHO Europe region

5.8.2 Background

The implementation of a multitude of immunization programmes in Europe over the last 30 years reduced illness and death due to vaccine-preventable diseases. Cases of measles were reduced by more than 90% between 1993 and 2007; and since 2002, Europe is polio-free (*Source*: http://www.euro.who.int/en/media-centre/events/events/2016/04/european-immunization-week-2016/background).

The fact that some vaccine preventable diseases have disappeared or are very rare following these vaccination programs can lead to parents believing there is no more need to vaccinate. Therefore, it is of huge importance that events like the European Immunization, helping maintain vaccination awareness and giving accurate and understandable information on immunization, exist. In this way, public confidence in immunization is less susceptible to be influenced by groups, websites or campaigns against vaccination. By acknowledging that every child deserves a healthy start in life, countries can use the European Immunization Week to increase awareness of the importance of immunization and to strengthen their immunization systems.

European
Immunization
Week
Prevent Protect Immunize

5.8.3 Project description

The project was implemented in collaboration with key stakeholders in Europe, including the United Nations Children's Fund (UNICEF) and the European Centre for Disease Prevention and Control (ECDC). The program is also supported, at national level, by ministers and ambassadors, and at regional level, by Her Royal Highness Crown Princess Mary of Denmark, the WHO Europe’s Patron and WHO Regional Director Zsuzsanna Jakab. Participation and engagement of these public figures to regional events of the EIW help increase awareness of the importance of immunization to the attention of decision-makers, parents, etc. and consequently, increase immunization coverage.

Several immunization partners support the initiative by providing countries with assistance for implementation activities at the national and sub-national level, including associations of health professionals, non-governmental organizations (NGOs) and civil society organizations.

The main objectives of this programme are to **increase awareness of the importance of immunization and to increase vaccination coverage**, with a particular focus on vulnerable or underserved populations (e.g. Roma and migrant communities, prisoners, refugees, young people etc.).

From its beginning in 2005 with eight pilot countries, EIW expanded each year to become a region-wide initiative including all 53 member states[18] of the Europe WHO region in 2015

Examples of such activities are:

- For the general public, vulnerable groups, parents and caregivers:
    - Organization of events such as theatre performances, concerts, sports events or press conferences highlighting key messages;
    - Dissemination of printed, video or other online information materials on the benefits of immunization;
    - Organization of specific outreach activities or catch-up immunization campaigns for vulnerable or underserved groups;
    - Organization of information campaigns on eventual changes to immunization programs e.g. shift to electronic vaccination registration;
    - Use of social media channels to disseminate key messages, generate discussions and answer vaccine-related queries or concerns.
- For health care professionals:
    - Organisation of training sessions for relevant health care staff, locally or nationally;
    - Dissemination of information material to health care workers, as well as guidance tools to educate parents about immunization.
- For policy and decision makers:
    - Organisation of workshops with political decision-makers discussing the challenges of immunization as well as providing information on the benefits of immunization;
    - Development of information materials containing relevant data and cost estimates to sensitize decision-makers to immunization-related challenges and issues.
- For the media:
    - Organization of press conferences to sensitize media to immunisation- related key issues and to generate positive media attention on the importance of vaccination;
    - Organization of workshops informing journalists about immunization, in order to get a balanced media coverage.

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[18] Albania, Andorra, Armenia, Austria, Azerbaijan, Belarus, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Luxembourg, Malta, Monaco, Montenegro, Netherlands, Norway, Poland, Portugal, Republic of Moldova, Romania, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Tajikistan, The former Yugoslav Republic of Macedonia, Turkey, Turkmenistan, Ukraine, United Kingdom of Great Britain and Northern Ireland, Uzbekistan

The European Immunization Week takes place each year in April. Several countries across the WHO Europe Region participate actively in this event, using the opportunity to promote immunization, either through communication campaigns or by vaccination of groups at high-risk.

2009

For instance, in 2009, 37 countries participated to the EIW, out of which 30 involved the Health Ministries in the projects planning phase; half involved mass media to raise awareness of immunization and EIW activities. Other countries involved medical associations, other ministries, some NGOs, the UNICEF and other United Nations agencies, and the ECDC. Main important themes of this EIW event were: vaccination in vulnerable populations, awareness of vaccination safety and importance in the general population, education of health staff, and increase in knowledge about immunization among politicians and decision makers.

2015 – 10th Anniversary of the EIW

In 2015, the EIW celebrated 10 years since its creation, and represented a great opportunity to raise awareness on the fact that despite a generally high European immunization coverage, there are still vulnerable communities or groups that remain under-immunized. The need to close these immunisation coverage gaps as soon as possible was the main theme of the EIW 2015.

The following examples are an illustration of actions being taken in several countries to identify and address gaps in immunization coverage, showing commitment at local, regional and national levels to improve the current status of immunization *(Source:* http://www.euro.who.int/en/media-centre/events/events/2015/04/european-immunization-week-2015/european-immunization-week-2015-commitment-to-immunization/commitment-to-close-immunization-gaps):

- **Small-scale approach more effective in closing immunity gaps in the Netherlands:**
  A health survey among parents waiting in line during one of the mass immunization day (September 2014) in the region was conducted in order to attempt transforming health services to better server parents and their children. Findings of this survey support the assumption that it was time to move immunization services out of massive gym halls and closer to people's lives and homes.

- **Tailored Immunization Programme (TIP) implementation in the United Kingdom:**

  Public Health England (PHE) together with the community, immunization service commissioners – National Health Service (NHS) England – and health providers, conducted a WHO tailoring immunization programme (TIP) project during 2014–2016 in the attempt to better understand reasons for current suboptimal coverage of children’s immunizations within this community. This project aimed to provide evidence-informed recommendations to immunization commissioners and providers, enabling better tailored to the needs of the community health services.

- **Estonia's Working Group on Communication of Infectious Diseases works to minimize impact of misinformation**

  In Estonia, leading authorities and partners in immunization activities discussed with WHO/Europe in March 2013 to attempt to identify national immunization programme threats and opportunities in terms of immunization advocacy and communications capacity and coordination. Meetings included key decision-makers at the Ministry of Social Affairs, the Health Board, the State Agency of Medicines, the Estonian Health Insurance Fund, the Estonian Society of Infectious Diseases and the Estonian Society of Family Doctors.

  This resulted in the official establishment in March 2014 of the *Working Group on Communication of Infectious Diseases*, aiming to organize effective communication activities and messages as well as risk and crisis-communication campaigns in the area of infectious diseases.

For the EIW 2016, an online forum (http://www.immunize-europe.org/) was created where all stakeholders and other interested parties can share information on country activities, share experiences/resources and lessons learned, or interact through discussion on immunization related topics.

5.8.4 Lessons learned and challenges

An evaluation of the program was conducted in 2009, after its fourth edition; reporting on the activities in the participating countries (37) and their impact on the immunization coverage and awareness (*Source:* http://www.euro.who.int/en/health-topics/disease-prevention/vaccines-and-immunization/publications/2010/evaluation-european-immunization-week-2009).

Of the participating countries, 90% considered the EIW 2009 a completely or partially successful event. Primary reasons being cited for problematic and/or less successful campaigns were: overlap with Easter holidays, the H1N1 influenza pandemic, late cancelations, lack of funding and plan changes following government changes.

Concerning the impact on vaccination coverage and awareness, one third of the participating countries reported increases in routine immunization coverage following the EIW 2009, with more than 60 000 people in specific target groups immunized in 11 countries. Nineteen countries expressed their confidence in an eventual increase of immunization coverage following the EIW 2009. However, all responders stressed out the fact that, most probably, the EIW would not have a long term impact on immunization coverage; thus, it is necessary to have an annual initiative.

5.8.5 Status of the project

The project is still ongoing; the European Immunization Week takes place every year. The next event is scheduled for the week of 23-29 April 2017, together with other WHO initiatives in the European Region as well as the World Immunization Week.

Source of images: *http://www.euro.who.int/*

5.8.6 Interview with Catharina de Kat

Name of the Best Practice: European Immunization Week (EIW)

Name of the person of contact:

Catharina de Kat, Communications, Web and Information Officer
Vaccine-preventable Diseases and Immunization

WHO Regional Office for Europe
Email: reynendekatc@who.int

Q1: How did this initiative start? What were the needs it addressed?

A: Immunization has led to a remarkable decline in suffering and death around the world. However in the early 2000s immunization coverage rates across the European Region were stagnating or in some cases even falling, in part due to the spread of misinformation about vaccines, including a supposed link between MMR and autism asserted in 1998 but later proven to be incorrect.

Countries across the Region recognized an increasing need to provide accurate, balanced and understandable information about the risks of diseases and the benefits of vaccination.

Member States of the WHO European Region expressed the need for a joint framework to boost awareness and strengthen their immunization systems, and in 2005 agreed on a resolution urging all European Region countries "to support, where appropriate, the implementation of an immunization week within the Region for advocacy to promote immunization" (WHO Regional Committee resolution EUR/RC55/R7).

The first European Immunization Week (EIW) was launched as a pilot in October 2005, with nine Member States participating: Belarus, Belgium, Hungary, Ireland, Italy, Russian Federation, Serbia, Tajikistan and the former Yugoslav Republic of Macedonia. Following the pilot, the next steps and lessons learnt were discussed at a meeting in Copenhagen with participation of 19 Member States.

Since 2007, EIW has taken place each year in April, and included a large number of activities aimed at reaching out to target groups through advocacy, communications and supplementary immunization.

Q2: Can you describe how civil society was included in your project?

A: EIW is a WHO-led initiative that is open and welcoming to all. At country level the event is embraced by a wide range of stakeholders including universities, community leaders, media, organizations of parents, patients and health professionals, parliaments, international agencies and local health facilities. The WHO Regional and country offices work with international partners (such as UNICEF, ECDC and Rotary International), ministries of health and public health institutes to help coordinate the campaign and provide support where needed.

A prominent example of civil society involvement in the 2017 EIW included high-profile activities organized by "Parents for Vaccination" in Ukraine.

See for example:

- http://www.euro.who.int/en/media-centre/events/events/2017/04/european-immunization-week-2017/news/news/2017/05/ngos-join-efforts-to-increase-immunization-coverage-in-ukraine
- http://www.euro.who.int/en/health-topics/disease-prevention/vaccines-and-immunization/publications/2017/highlights-of-european-immunization-week-2017-narrative-report

Q3: Why do you think it was important to include civil society in your project?

A: Protecting people of all ages from vaccine-preventable diseases concerns everyone, and can only be accomplished with everyone on board. Every context is different, but we know that trust - in vaccines and in the people and institutions that provide them - is a key factor for sustaining high immunization rates. EIW provides the opportunity for all stakeholders to stand aligned in promoting this important public health message and ensure that messages about the safety and importance of vaccines are reaching key target audiences.

Q4: What was found to influence the attitudes / beliefs of the population towards vaccination?

A: While every context is different, we know that to ensure public trust in vaccines and health authorities, as well as resilience to vaccine safety scares, ongoing communications are needed to build awareness of the benefits of immunization and risks of diseases. This involves listening to and responding to the concerns of parents, addressing misperceptions and shaping messages to fit the target audiences. It also involves ensuring convenient service provision in an environment and with a health worker that help parents and those being vaccinated feel safe and comforted.

Q5: What types of activities / campaigns were found to be the most efficient?

A: EIW campaigns are planned based on the context and challenges in each country. Over the years we have seen EIW campaigns making use of radio, television, social media, sports events, school classrooms, university lectures, parliamentary discussions, flash mobs, outreach to health professionals and much more to spread targeted messages. In some cases, the aim is simply to educate, while at other times it is to reach vulnerable subgroups with supplemental immunization activities or to introduce a new appointment system or clinic opening hours. Although organized under the same umbrella, every national EIW campaign is unique, requiring its own set of activities and assessments.

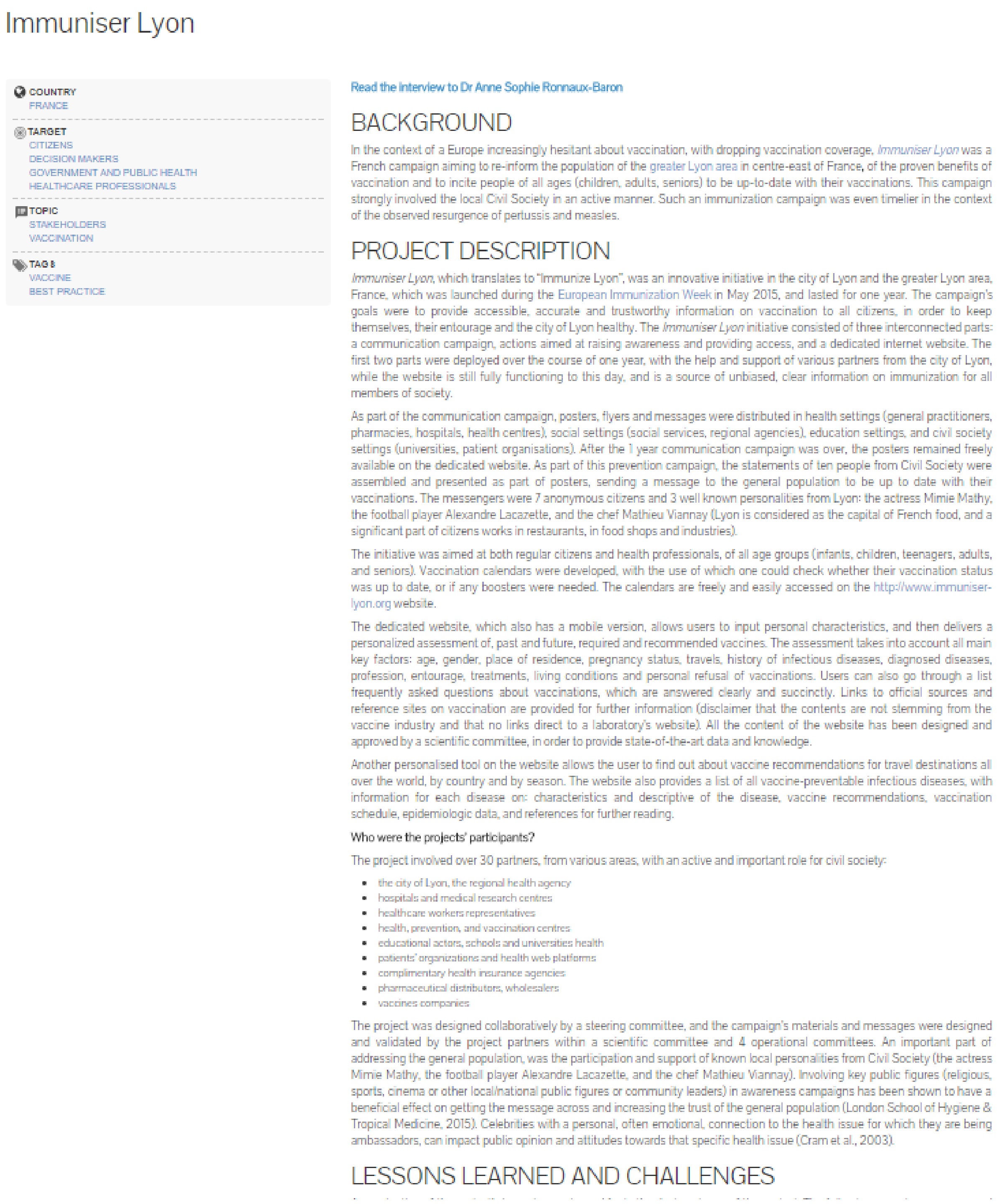
Q6: Was there an evaluation of the project conducted? If yes, what were the results?

A: Each country assesses its activity and involvement in its own way, based on the context and aims. Direct impact on uptake over a longer period is difficult to measure, but certainly the number of people who are reached by the messages being communicated can serve as a proxy for positive impact. Recently Austria confirmed the impact of their campaign by measuring increased uptake of immunization services during the week of EIW, when expanded clinic opening hours were being tested (See: https://www.ncbi.nlm.nih.gov/pubmed/28797728).

Q7: How does the implementation of the project across European countries differ?

A: The 53 Member States of the WHO European Region are highly diverse in terms of their history, cultures, traditions, languages, income, health systems and service provision. This is reflected in the many ways EIW is used to reach the general public or specific target groups. In 2017 alone, hundreds of activities were reported by 30 countries across the Region in addition to development of information materials, press coverage and social media campaigns. These varied from banners on public buses in Kazakhstan to letters to paediatricians in Switzerland; and from a review of children's immunization records in Malta to a national scientific conference on life-long vaccination in Poland. More examples of the many activities reported is available on the Immunize Europe Forum: (http://www.immunize-europe.org/calendar/event/71-european-immunization-week-2017/), where countries can showcase the work they are doing during EIW and throughout the year to increase awareness and immunization coverage.

5.9 Immuniser Lyon



Immuniser Lyon

COUNTRY
FRANCE

TARGET
CITIZENS
DECISION MAKERS
GOVERNMENT AND PUBLIC HEALTH
HEALTHCARE PROFESSIONALS

TOPIC
STAKEHOLDERS
VACCINATION

TAGS
VACCINE
BEST PRACTICE

Read the interview to Dr Anne Sophie Ronnaux-Baron

BACKGROUND

In the context of a Europe increasingly hesitant about vaccination, with dropping vaccination coverage, *Immuniser Lyon* was a French campaign aiming to re-inform the population of the greater Lyon area in centre-east of France, of the proven benefits of vaccination and to incite people of all ages (children, adults, seniors) to be up-to-date with their vaccinations. This campaign strongly involved the local Civil Society in an active manner. Such an immunization campaign was even timelier in the context of the observed resurgence of pertussis and measles.

PROJECT DESCRIPTION

Immuniser Lyon, which translates to "Immunize Lyon", was an innovative initiative in the city of Lyon and the greater Lyon area, France, which was launched during the European Immunization Week in May 2015, and lasted for one year. The campaign's goals were to provide accessible, accurate and trustworthy information on vaccination to all citizens, in order to keep themselves, their entourage and the city of Lyon healthy. The *Immuniser Lyon* initiative consisted of three interconnected parts: a communication campaign, actions aimed at raising awareness and providing access, and a dedicated internet website. The first two parts were deployed over the course of one year, with the help and support of various partners from the city of Lyon, while the website is still fully functioning to this day, and is a source of unbiased, clear information on immunization for all members of society.

As part of the communication campaign, posters, flyers and messages were distributed in health settings (general practitioners, pharmacies, hospitals, health centres), social settings (social services, regional agencies), education settings, and civil society settings (universities, patient organisations). After the 1 year communication campaign was over, the posters remained freely available on the dedicated website. As part of this prevention campaign, the statements of ten people from Civil Society were assembled and presented as part of posters, sending a message to the general population to be up to date with their vaccinations. The messengers were 7 anonymous citizens and 3 well known personalities from Lyon: the actress Mimie Mathy, the football player Alexandre Lacazette, and the chef Mathieu Viannay (Lyon is considered as the capital of French food, and a significant part of citizens works in restaurants, in food shops and industries).

The initiative was aimed at both regular citizens and health professionals, of all age groups (infants, children, teenagers, adults, and seniors). Vaccination calendars were developed, with the use of which one could check whether their vaccination status was up to date, or if any boosters were needed. The calendars are freely and easily accessed on the http://www.immuniser-lyon.org website.

The dedicated website, which also has a mobile version, allows users to input personal characteristics, and then delivers a personalized assessment of, past and future, required and recommended vaccines. The assessment takes into account all main key factors: age, gender, place of residence, pregnancy status, travels, history of infectious diseases, diagnosed diseases, profession, entourage, treatments, living conditions and personal refusal of vaccinations. Users can also go through a list frequently asked questions about vaccinations, which are answered clearly and succinctly. Links to official sources and reference sites on vaccination are provided for further information (disclaimer that the contents are not stemming from the vaccine industry and that no links direct to a laboratory's website). All the content of the website has been designed and approved by a scientific committee, in order to provide state-of-the-art data and knowledge.

Another personalised tool on the website allows the user to find out about vaccine recommendations for travel destinations all over the world, by country and by season. The website also provides a list of all vaccine-preventable infectious diseases, with information for each disease on: characteristics and descriptive of the disease, vaccine recommendations, vaccination schedule, epidemiologic data, and references for further reading.

Who were the projects' participants?

The project involved over 30 partners, from various areas, with an active and important role for civil society:

- the city of Lyon, the regional health agency
- hospitals and medical research centres
- healthcare workers representatives
- health, prevention, and vaccination centres
- educational actors, schools and universities health
- patients' organizations and health web platforms
- complimentary health insurance agencies
- pharmaceutical distributors, wholesalers
- vaccines companies

The project was designed collaboratively by a steering committee, and the campaign's materials and messages were designed and validated by the project partners within a scientific committee and 4 operational committees. An important part of addressing the general population, was the participation and support of known local personalities from Civil Society (the actress Mimie Mathy, the football player Alexandre Lacazette, and the chef Mathieu Viannay). Involving key public figures (religious, sports, cinema or other local/national public figures or community leaders) in awareness campaigns has been shown to have a beneficial effect on getting the message across and increasing the trust of the general population (London School of Hygiene & Tropical Medicine, 2015). Celebrities with a personal, often emotional, connection to the health issue for which they are being ambassadors, can impact public opinion and attitudes towards that specific health issue (Cram et al., 2003).

LESSONS LEARNED AND CHALLENGES

5.9.1 Factsheet

GOOD PRACTICE NAME: Immuniser Lyon

MAIN THEME: health care workers, vaccination, communication

SPECIFIC Sub-THEME: increasing the propensity of health-care workers to vaccinate, propensity to vaccinate, communication campaign

COUNTRY: France

KEYWORDS: vaccination, communication campaign, celebrity ambassadors

START DATE: May 2015

END DATE: May 2016

KEY OBJECTIVES: provide accessible, accurate and trustworthy information on vaccination to all citizens; encourage vaccination

WEBSITE: **http://www.immuniser-lyon.org/**

CONTACT PERSONS (email):

PROJECT INITIATORS: project partners included regional health agencies, the city of Lyon, hospitals, healthcare workers' representatives, patients' organisations, and vaccines companies, among others

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: local level

5.9.2 Background

In the context of a Europe increasingly hesitant about vaccination, with dropping vaccination coverage, *Immuniser Lyon* (http://www.immuniser-lyon.org/) was a French campaign aiming to re-inform the population of the greater Lyon area (https://en.wikipedia.org/wiki/Metropolitan_Lyon) in centre-east of France**,** of the proven benefits of vaccination and to incite people of all ages (children, adults, seniors) to be up-to-date with their vaccinations. This campaign strongly involved the local Civil Society in an active manner.

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Who were the projects' participants?

The project involved over 30 partners, from various areas, with an active and important role for civil society:

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- educational actors, schools and universities health
- patients' organizations and health web platforms
- complimentary health insurance agencies
- pharmaceutical distributors, wholesalers
- vaccines companies

The project was designed collaboratively by a steering committee, and the campaign's materials and messages were designed and validated by the project partners within a scientific committee and 4 operational committees.

An important part of addressing the general population, was the participation and support of known local personalities from Civil Society (the actress Mimie Mathy, the football player Alexandre Lacazette, and the chef Mathieu Viannay). Involving key public figures (religious, sports, cinema or other local/national public figures or community leaders) in awareness campaigns has been shown to have a beneficial effect on getting the message across and increasing the trust of the general population (London School of Hygiene & Tropical Medicine, 2015). Celebrities with a personal, often emotional, connection to the health issue for which they are being ambassadors, can impact public opinion and attitudes towards that specific health issue (Cram et al., 2003).

5.9.4 Lessons learned and challenges

An evaluation of the project's impact was planned for in the design stages of the project. The following aspects were assessed in order to evaluate the "I*mmuniser Lyon*" initiative (Faurié-Gauthier, 2016):

- online survey of public, pharmacists', students', nurses' opinions on vaccination adherence and on how the campaign was perceived
- number of partners engaged in the project
- number of posters and flyers distributed
- number of actions in Lyon
- media coverage
- website statistics (traffic, referencing on Google, number of support votes, etc.)

Preliminary results of these evaluations showed high media coverage, new collaborations emerging, and support for the initiative from decision makers, national experts, and health professionals' unions. No anti-vaccinations attacks or controversies were observed (Faurié-Gauthier, 2016).

The project received 2 prizes: the gold prize for Public Health Communication at the Health Communication festival, and a poster describing the project received in 2015 the audience award at the "États Généraux de la Santé en Régions" (General States of health in the Regions) meeting.

For the elaboration of messages and for choosing the best course of action, social psychologists were involved in the decisional process. They were able to guide the messages towards promoting health (and not fearing disease) and motivating people to verify if they are up to date with their vaccinations. Also, by creating messages targeted at different groups (health care workers, seniors, teenagers, adults), people would more easily identify with one of them (Faurié-Gauthier, 2016).

5.9.5 Status of the project

The communication campaign part of the project is terminated, however the dedicated website with all its tools is continuously available online. The "Immuniser Lyon" project participated in the French citizen consultation on vaccination, and also helped promote the "Electronic Vaccination Booklet" which has been tested in Lyon (http://www.ra-sante.com/lyon-lancement-carnet-de-vaccination-electronique-125530.html).

5.9.6 References

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Faurié-Gauthier C. Immuniser Lyon - Territoires et santé: quels enjeux? RFVS - OMS, 2016 [cited 13 Feb 2017]. Available from: http://www.villes-sante.com/wp-content/uploads/AT3_presentation_Lyon_31mai2016.pdf.

London School of Hygiene & Tropical Medicine. The state of vaccine confidence. 2015.
Available from: http://www.vaccineconfidence.org/research/the-state-of-vaccine-confidence/

5.9.7 Interview with Dr. Anne Sophie Ronnaux-Baron

Name of the Best Practice: Immuniser Lyon

Name of the person of contact: *Dr Anne Sophie Ronnaux-Baron cdhs@cdhs.fr*

Q1: How did this initiative start? What were the needs it addressed?

A: The initiative began in 2015, due to the realization that some vaccination programs were being challenged and that there was an increase in mistrust in France.

To meet these concerns, the main objective of the Immuniser Lyon program was to raise awareness among stakeholders and the general population about infectious disease prevention and lifelong immunization. It was the first time a project was based on the initiative and actions of an independent public-private collective in the metropolitan area of Lyon.

Q2: Can you describe how civil society was included in your project?

A: The Immuniser Lyon collective relays to be present and to answer the questions of the general public during numerous events involving people of all ages. Patient associations and health networks are partners in the initiative.

Q3: Why do you think it was important to include civil society in your project?

A: In order to answer a need for information. Indeed, many studies confirm that the French population has many questions to ask about vaccination.

The association of more than 35 partners marks an institutional commitment, reinforces the importance of defending vaccination and organizing a reference network to find reliable, verified and referenced information.

Q4: What was found to influence the attitudes / beliefs of the population towards vaccination?

A: The vast majority of French people are hesitant regarding vaccination because of conflicting messages in the press and the media. Being able to talk directly with them, listen to them and provide them a platform for voicing their concerns and questions is sufficient to provide reassurance.

Q5: Are adults and older people also concerned by vaccines?

A: Of course, vaccination concerns all citizens, regardless of age, for them or their families. Immunization protects against infectious diseases at all ages.

Q6: What trustworthy information sources for websites would you recommend?

A: Immuniser Lyon recommends all websites of health authorities: vaccination-info-service.fr, Public Health France, mesvaccins.net ...

Q7: What is the main message Immuniser Lyon wants to communicate?

A: Immuniser Lyon invites health professionals and the general public to check their vaccination status, with the slogan: for us it's done!

Q8: Was there an evaluation of the project conducted? If yes, what were the results?

A: Several qualitative and quantitative evaluations are ongoing.

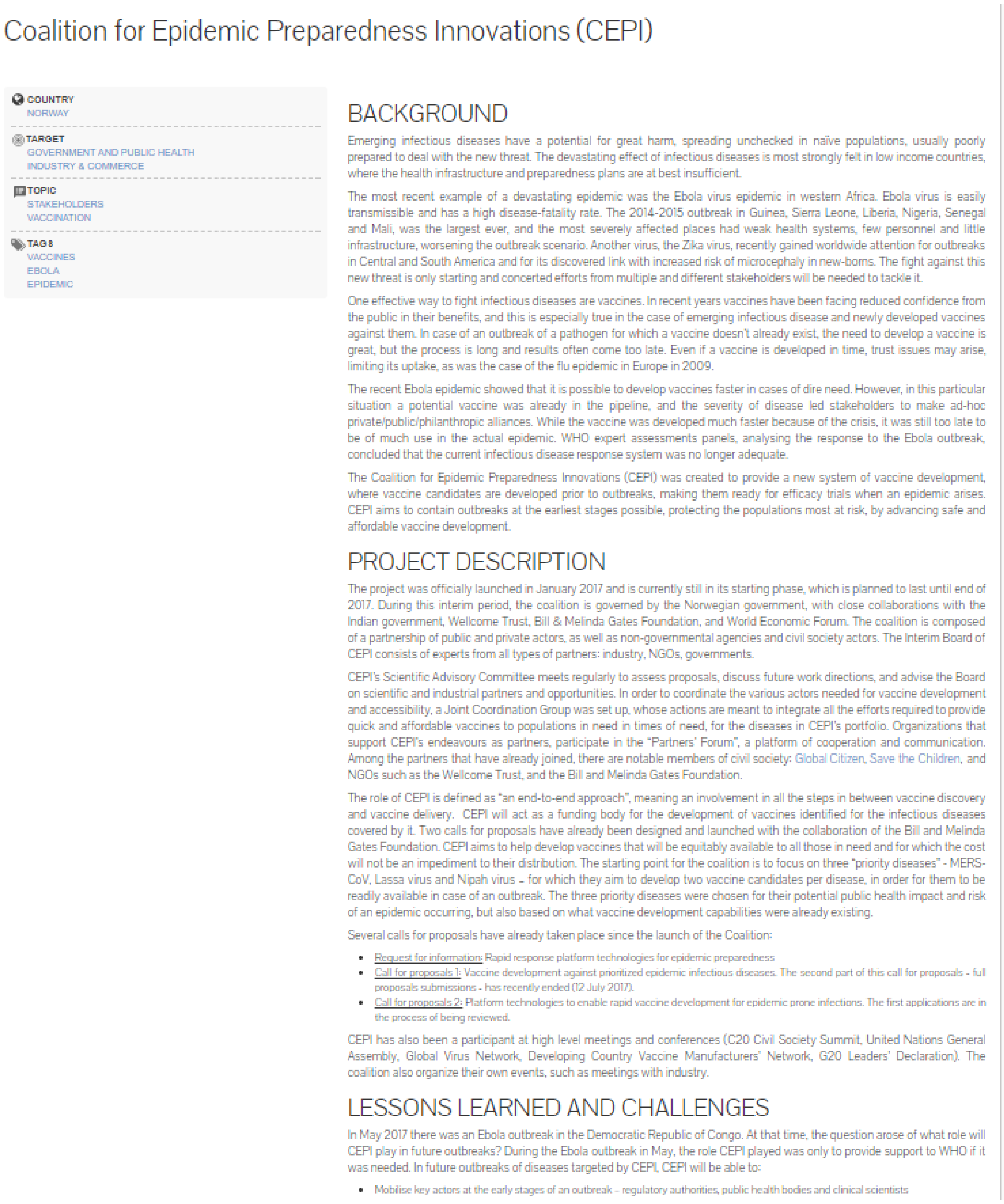
Q9: Do you think your project could be implemented in other regions / countries / communities? Has this already been the case?

A: Yes this is already the case in Nice with Vacci 'Nice, and other projects are underway in Montpellier, Bordeaux and Nantes.

Q10: Please feel free to add any other comments you might have.

A: You will find on our website, the news from the project partners and up-to-date vaccination recommendations. We remain at your disposal for further information.

5.10 Coalition for Epidemic Preparedness Innovations (CEPI)



Coalition for Epidemic Preparedness Innovations (CEPI)

COUNTRY
NORWAY

TARGET
GOVERNMENT AND PUBLIC HEALTH
INDUSTRY & COMMERCE

TOPIC
STAKEHOLDERS
VACCINATION

TAGS
VACCINES
EBOLA
EPIDEMIC

BACKGROUND

Emerging infectious diseases have a potential for great harm, spreading unchecked in naïve populations, usually poorly prepared to deal with the new threat. The devastating effect of infectious diseases is most strongly felt in low income countries, where the health infrastructure and preparedness plans are at best insufficient.

The most recent example of a devastating epidemic was the Ebola virus epidemic in western Africa. Ebola virus is easily transmissible and has a high disease-fatality rate. The 2014-2015 outbreak in Guinea, Sierra Leone, Liberia, Nigeria, Senegal and Mali, was the largest ever, and the most severely affected places had weak health systems, few personnel and little infrastructure, worsening the outbreak scenario. Another virus, the Zika virus, recently gained worldwide attention for outbreaks in Central and South America and for its discovered link with increased risk of microcephaly in new-borns. The fight against this new threat is only starting and concerted efforts from multiple and different stakeholders will be needed to tackle it.

One effective way to fight infectious diseases are vaccines. In recent years vaccines have been facing reduced confidence from the public in their benefits, and this is especially true in the case of emerging infectious disease and newly developed vaccines against them. In case of an outbreak of a pathogen for which a vaccine doesn't already exist, the need to develop a vaccine is great, but the process is long and results often come too late. Even if a vaccine is developed in time, trust issues may arise, limiting its uptake, as was the case of the flu epidemic in Europe in 2009.

The recent Ebola epidemic showed that it is possible to develop vaccines faster in cases of dire need. However, in this particular situation a potential vaccine was already in the pipeline, and the severity of disease led stakeholders to make ad-hoc private/public/philanthropic alliances. While the vaccine was developed much faster because of the crisis, it was still too late to be of much use in the actual epidemic. WHO expert assessments panels, analysing the response to the Ebola outbreak, concluded that the current infectious disease response system was no longer adequate.

The Coalition for Epidemic Preparedness Innovations (CEPI) was created to provide a new system of vaccine development, where vaccine candidates are developed prior to outbreaks, making them ready for efficacy trials when an epidemic arises. CEPI aims to contain outbreaks at the earliest stages possible, protecting the populations most at risk, by advancing safe and affordable vaccine development.

PROJECT DESCRIPTION

The project was officially launched in January 2017 and is currently still in its starting phase, which is planned to last until end of 2017. During this interim period, the coalition is governed by the Norwegian government, with close collaborations with the Indian government, Wellcome Trust, Bill & Melinda Gates Foundation, and World Economic Forum. The coalition is composed of a partnership of public and private actors, as well as non-governmental agencies and civil society actors. The Interim Board of CEPI consists of experts from all types of partners: industry, NGOs, governments.

CEPI's Scientific Advisory Committee meets regularly to assess proposals, discuss future work directions, and advise the Board on scientific and industrial partners and opportunities. In order to coordinate the various actors needed for vaccine development and accessibility, a Joint Coordination Group was set up, whose actions are meant to integrate all the efforts required to provide quick and affordable vaccines to populations in need in times of need, for the diseases in CEPI's portfolio. Organizations that support CEPI's endeavours as partners, participate in the "Partners' Forum", a platform of cooperation and communication. Among the partners that have already joined, there are notable members of civil society: Global Citizen, Save the Children, and NGOs such as the Wellcome Trust, and the Bill and Melinda Gates Foundation.

The role of CEPI is defined as "an end-to-end approach", meaning an involvement in all the steps in between vaccine discovery and vaccine delivery. CEPI will act as a funding body for the development of vaccines identified for the infectious diseases covered by it. Two calls for proposals have already been designed and launched with the collaboration of the Bill and Melinda Gates Foundation. CEPI aims to help develop vaccines that will be equitably available to all those in need and for which the cost will not be an impediment to their distribution. The starting point for the coalition is to focus on three "priority diseases" - MERS-CoV, Lassa virus and Nipah virus – for which they aim to develop two vaccine candidates per disease, in order for them to be readily available in case of an outbreak. The three priority diseases were chosen for their potential public health impact and risk of an epidemic occurring, but also based on what vaccine development capabilities were already existing.

Several calls for proposals have already taken place since the launch of the Coalition:

- Request for information: Rapid response platform technologies for epidemic preparedness
- Call for proposals 1: Vaccine development against prioritized epidemic infectious diseases. The second part of this call for proposals - full proposals submissions - has recently ended (12 July 2017).
- Call for proposals 2: Platform technologies to enable rapid vaccine development for epidemic prone infections. The first applications are in the process of being reviewed.

CEPI has also been a participant at high level meetings and conferences (C20 Civil Society Summit, United Nations General Assembly, Global Virus Network, Developing Country Vaccine Manufacturers' Network, G20 Leaders' Declaration). The coalition also organize their own events, such as meetings with industry.

LESSONS LEARNED AND CHALLENGES

In May 2017 there was an Ebola outbreak in the Democratic Republic of Congo. At that time, the question arose of what role will CEPI play in future outbreaks? During the Ebola outbreak in May, the role CEPI played was only to provide support to WHO if it was needed. In future outbreaks of diseases targeted by CEPI, CEPI will be able to:

- Mobilise key actors at the early stages of an outbreak – regulatory authorities, public health bodies and clinical scientists

5.10.1 Factsheet

GOOD PRACTICE NAME: Coalition for Epidemic Preparedness Innovations

MAIN THEME: vaccination

SPECIFIC Sub-THEME: international cooperation, preparedness

COUNTRY: international collaboration

KEYWORDS: international, coalition, vaccines, funding

START DATE: officially launched in January 2017

END DATE: ongoing

KEY OBJECTIVES: preparedness for infectious disease outbreaks through investments in vaccine development

WEBSITE: cepi.net

CONTACT PERSONS (email): Interim Secretariat can be contacted at info@cepi.net

PROJECT INITIATORS: a consortium of international organisations, governments, industry, public and philanthropic R&D funders, academia, NGOs and civil society groups started the project during the 2016 World Economic Forum in Davos

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: international

5.10.2 Background

Emerging infectious diseases have a potential for great harm, spreading unchecked in naïve populations, usually poorly prepared to deal with the new threat. The devastating effect of infectious diseases is most strongly felt in low income countries, where the health infrastructure and preparedness plans are at best insufficient.

The most recent example of a devastating epidemic was the Ebola virus epidemic in western Africa. Ebola virus is easily transmissible and has a high disease-fatality rate. The 2014-2015 outbreak in Guinea, Sierra Leone, Liberia, Nigeria, Senegal and Mali, was the largest ever, and the most severely affected places had weak health systems, few personnel and little infrastructure, worsening the outbreak scenario. Another virus, the Zika virus, recently gained worldwide attention for outbreaks in Central and South America and for its discovered link with increased risk of microcephaly in new-borns. The fight against this new threat is only starting and concerted efforts from multiple and different stakeholders will be needed to tackle it.

One effective way to fight infectious diseases are vaccines. In recent years vaccines have been facing reduced confidence from the public in their benefits, and this is especially true in the case of emerging infectious disease and newly developed vaccines against them. In case of an outbreak of a pathogen for which a vaccine doesn't already exist, the need to develop a vaccine is great, but the process is long and results often come too late. Even if a vaccine is developed in time, trust issues may arise, limiting its uptake, as was the case of the flu epidemic in Europe in 2009.

The recent Ebola epidemic showed that it is possible to develop vaccines faster in cases of dire need. However, in this particular situation a potential vaccine was already in the pipeline, and the severity of disease led stakeholders to make ad-hoc private/public/philanthropic alliances. While the vaccine was developed much faster because of the crisis, it was still too late to be of much use in the actual epidemic. WHO expert assessments panels, analysing the response to the Ebola outbreak, concluded that the current infectious disease response system was no longer adequate.

The Coalition for Epidemic Preparedness Innovations (CEPI) was created to provide a new system of vaccine development, where vaccine candidates are developed prior to outbreaks, making them ready for efficacy trials when an epidemic arises. CEPI aims to contain outbreaks at the earliest stages possible, protecting the populations most at risk, by advancing safe and affordable vaccine development.

5.10.3 Project description

The project was officially launched in January 2017 and is currently still in its starting phase, which is planned to last until end of 2017. During this interim period, the coalition is governed by the Norwegian government, with close collaborations with the Indian government, Wellcome Trust, Bill & Melinda Gates Foundation, and World Economic Forum. The coalition is composed of a partnership of public and private actors, as well as non-governmental agencies and civil society actors. The Interim Board of CEPI consists of experts from all types of partners: industry, NGOs, governments.

CEPI's Scientific Advisory Committee meets regularly to assess proposals, discuss future work directions, and advise the Board on scientific and industrial partners and opportunities. In order to coordinate the various actors needed for vaccine development and accessibility, a Joint Coordination Group was set up, whose actions are meant to integrate all the efforts required to provide quick and affordable vaccines to populations in need in times of need, for the diseases in CEPI's portfolio.

Organizations that support CEPI's endeavours as partners, participate in the "Partners' Forum", a platform of cooperation and communication. Among the partners that have already joined, there are notable members of civil society: Global Citizen, Save the Children, and NGOs such as the Wellcome Trust, and the Bill and Melinda Gates Foundation.

The role of CEPI is defined as "an end-to-end approach", meaning an involvement in all the steps in between vaccine discovery and vaccine delivery. CEPI will act as a funding body for the development of vaccines identified for the infectious diseases covered by it. Two calls for proposals have already been designed and launched with the collaboration of the Bill and Melinda Gates Foundation. CEPI aims to help develop vaccines that will be equitably available to all those in need and for which the cost will not be an impediment to their distribution.

The starting point for the coalition is to focus on three "priority diseases" - MERS-CoV, Lassa virus and Nipah virus – for which they aim to develop two vaccine candidates per disease, in order for them to be readily available in case of an outbreak. The three priority diseases were chosen for their potential public health impact and risk of an epidemic occurring, but also based on what vaccine development capabilities were already existing.

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CEPI has also been a participant at high level meetings and conferences (C20 Civil Society Summit, United Nations General Assembly, Global Virus Network, Developing Country Vaccine Manufacturers' Network, G20 Leaders' Declaration). The coalition also organize their own events, such as meetings with industry.

5.10.4 Lessons learned and challenges

In May 2017 there was an Ebola outbreak in the Democratic Republic of Congo. At that time, the question arose of what role will CEPI play in future outbreaks? During the Ebola outbreak in May, the role CEPI played was only to provide support to WHO if it was needed. In future outbreaks of diseases targeted by CEPI, CEPI will be able to:

- Mobilise key actors at the early stages of an outbreak – regulatory authorities, public health bodies and clinical scientists
- Call upon strong partnerships with organisations able to send medical personnel and support in case of outbreaks – such as Médecins Sans Frontières (Doctors Without Borders).

The development of partnerships needs to happen before an outbreak occurs.

5.10.5 Status of the project

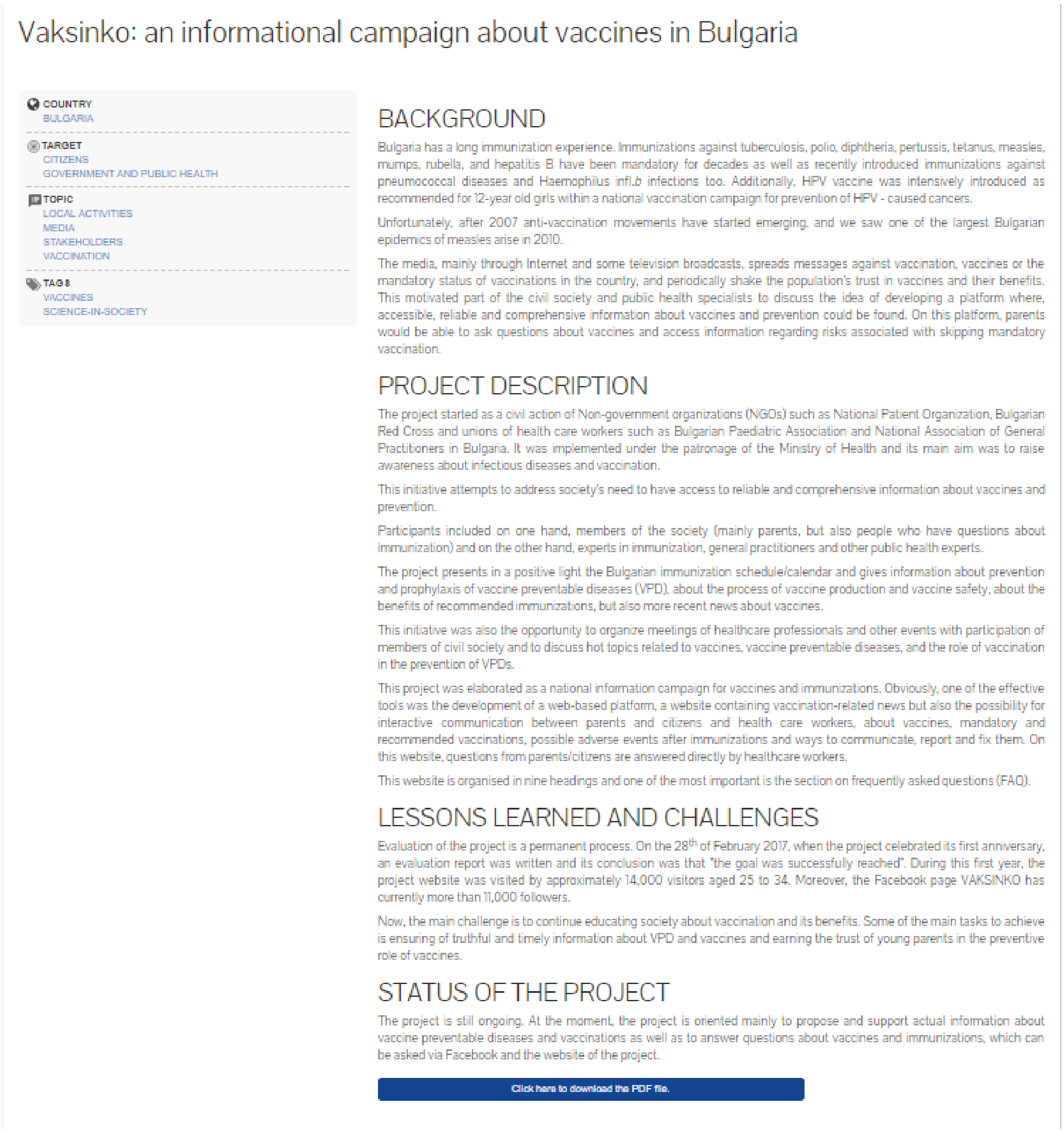
The project is forging ahead, moving towards a transition from the interim stage to a definitive format. The current newsletter is released once a month, with a direct address from the CEPI CEO included. The coalition stresses their commitment to open communication and transparency of actions.

The call for applications for the second stage of the 2nd call for proposals was issued, and the 4th meeting of the CEPI scientific advisory committee was held to evaluate them. Selected partnerships will be announced at a later date.

CEPI will continue to work towards accelerating the vaccine research for the three diseases chosen as priority diseases, and also towards extending their scope further to other infectious diseases lacking a vaccine and having a pandemic spread potential.

The model on which CEPI is based - involving various stakeholders, establishing wide ranging partnerships, and including civil society - is being successfully applied to other endeavours related to vaccines and health innovation (such as PATH, HEAL Alliance, Gavi).

5.11 Vaksinko: an informational campaign about vaccines in Bulgaria



Vaksinko: an informational campaign about vaccines in Bulgaria

BACKGROUND

Bulgaria has a long immunization experience. Immunizations against tuberculosis, polio, diphtheria, pertussis, tetanus, measles, mumps, rubella, and hepatitis B have been mandatory for decades as well as recently introduced immunizations against pneumococcal diseases and Haemophilus infl.*b* infections too. Additionally, HPV vaccine was intensively introduced as recommended for 12-year old girls within a national vaccination campaign for prevention of HPV - caused cancers.

Unfortunately, after 2007 anti-vaccination movements have started emerging, and we saw one of the largest Bulgarian epidemics of measles arise in 2010.

The media, mainly through Internet and some television broadcasts, spreads messages against vaccination, vaccines or the mandatory status of vaccinations in the country, and periodically shake the population's trust in vaccines and their benefits. This motivated part of the civil society and public health specialists to discuss the idea of developing a platform where, accessible, reliable and comprehensive information about vaccines and prevention could be found. On this platform, parents would be able to ask questions about vaccines and access information regarding risks associated with skipping mandatory vaccination.

PROJECT DESCRIPTION

The project started as a civil action of Non-government organizations (NGOs) such as National Patient Organization, Bulgarian Red Cross and unions of health care workers such as Bulgarian Paediatric Association and National Association of General Practitioners in Bulgaria. It was implemented under the patronage of the Ministry of Health and its main aim was to raise awareness about infectious diseases and vaccination.

This initiative attempts to address society's need to have access to reliable and comprehensive information about vaccines and prevention.

Participants included on one hand, members of the society (mainly parents, but also people who have questions about immunization) and on the other hand, experts in immunization, general practitioners and other public health experts.

The project presents in a positive light the Bulgarian immunization schedule/calendar and gives information about prevention and prophylaxis of vaccine preventable diseases (VPD), about the process of vaccine production and vaccine safety, about the benefits of recommended immunizations, but also more recent news about vaccines.

This initiative was also the opportunity to organize meetings of healthcare professionals and other events with participation of members of civil society and to discuss hot topics related to vaccines, vaccine preventable diseases, and the role of vaccination in the prevention of VPDs.

This project was elaborated as a national information campaign for vaccines and immunizations. Obviously, one of the effective tools was the development of a web-based platform, a website containing vaccination-related news but also the possibility for interactive communication between parents and citizens and health care workers, about vaccines, mandatory and recommended vaccinations, possible adverse events after immunizations and ways to communicate, report and fix them. On this website, questions from parents/citizens are answered directly by healthcare workers.

This website is organised in nine headings and one of the most important is the section on frequently asked questions (FAQ).

LESSONS LEARNED AND CHALLENGES

Evaluation of the project is a permanent process. On the 28th of February 2017, when the project celebrated its first anniversary, an evaluation report was written and its conclusion was that "the goal was successfully reached". During this first year, the project website was visited by approximately 14,000 visitors aged 25 to 34. Moreover, the Facebook page VAKSINKO has currently more than 11,000 followers.

Now, the main challenge is to continue educating society about vaccination and its benefits. Some of the main tasks to achieve is ensuring of truthful and timely information about VPD and vaccines and earning the trust of young parents in the preventive role of vaccines.

STATUS OF THE PROJECT

The project is still ongoing. At the moment, the project is oriented mainly to propose and support actual information about vaccine preventable diseases and vaccinations as well as to answer questions about vaccines and immunizations, which can be asked via Facebook and the website of the project.

5.11.1 Factsheet

GOOD PRACTICE NAME: Vaksinko, an informational campaign about vaccines in Bulgaria

MAIN THEME: vaccination, social media and internet

SPECIFIC Sub-THEME: information about vaccines and prevention, increasing awareness about vaccines

COUNTRY: Bulgaria

KEYWORDS: vaccination, social media, internet

START DATE: 09th of February 2016

END DATE: The project is still ongoing.

KEY OBJECTIVES:

- To provide accessible, reliable and comprehensive information about vaccines and prevention as well as information about the dangers of skipping mandatory vaccination
- To give parents the opportunity to ask vaccines-related questions
- To show the benefits of adherence to the mandatory immunization calendar
- To inform about opportunities to report side-effects of vaccines

WEBSITE: http://vaksinko.bg/

CONTACT PERSONS (email): contact form is available on the website. Contact phone number provided - +359(0)70010515

PROJECT INITIATORS: National Patient Organization, Bulgarian Red Cross, Bulgarian Paediatric Association, and National Association of General Practitioners in Bulgaria and under the patronage of the Ministry of Health**.**

IMPLEMENTED AT NATIONAL/LOCAL LEVEL: National

5.11.2 Background

Bulgaria has a long immunization experience. Immunizations against tuberculosis, polio, diphtheria, pertussis, tetanus, measles, mumps, rubella, and hepatitis B have been mandatory for decades as well as recently introduced immunizations against pneumococcal diseases and Haemophilus infl.*b* infections too. Additionally, HPV vaccine was intensively introduced as recommended for 12-year old girls within a national vaccination campaign for prevention of HPV - caused cancers.

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5.11.5 Status of the project

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6 Best Practices Guidelines

A guideline is meant as “Recommended practice that allows some discretion or leeway in its interpretation, implementation, or use.” The source of this definition is the same source we chose for the definition of “best practice”: http://www.businessdictionary.com/definition/guideline.html”.

It follows that writing a guideline concerning Best Practices is a form of meta-practice, since one has to describe a practice that has to guide other practices. This is of course, different from a therapeutic guideline, where the practice has to guide a specific action (although complex).

Another issue of interest is how to design a guideline. Indeed, guidelines can have very heterogeneous degrees of complexity, depending on the reference domain.

In our case, the reference domain has huge potentialities, but from the factual point of view it is very restricted, as exhaustively shown in the previous sections of this report. Given the paucity of the primary material, our guidelines are written as a series of simple recommendations.

Thus, the guidelines present in a synthesized format the key messages derived from the collection of good practices assembled on the platform.

It is to be observed that in the elaboration of these guidelines we took into account both common positive aspects of the various practices we collected, but also their main negative issues.

One important aspect that became quickly evident was that there is a limited space for “general” guidelines for civil society involvement.

Not surprisingly, the good practices that we collected in the portal are coherent with some of the principles of the “ASSET Roadmap for Responsible Research and Innovation” elaborated in the Task 3.2 of our Project, and the few general guidelines are coherent too with some key points of the roadmap:

1. Although collected practices are good examples to be imitated, in many of them the relationship between PH stakeholders unfortunately remains substantially asymmetrical due to differences in backgrounds and mutual communication problems. Therefore, a first guideline could consist in making an effort to mitigate these problems from the inception phase of the project.
2. Civil Society (CS) has to be involved in all key phases of a PH research or PH action. In this way, CS representatives will feel as intellectual co-owners: co-researchers of PH researches or co-designer of PH actions.
3. A good practice should be an opportunity of mutual learning for both PH scientist/officers and Civil Society representatives. In the main collected good practices, both parties changed their perceptions of what is PH during the project.
4. In particular, a good practice must be a way for SHs to learn about issues of which they were previously unaware.
5. Good Practices concerning Epidemics and Pandemics must primarily be conceived to involve potential patients and their relatives. Thus, the possibility of translating Public Engagement practices from other fields of PH is limited. Indeed, for chronic diseases, the willingness of involvement of associations of patients is huge, but in the case of epidemics and pandemics, it is limited only to a small number of cases.
6. Social Media and the web must not be conceived merely as the communication component of the practice, but as an integral (and fundamental) part of the practice.
7. Research-related practices should have a dissemination plan based on one hand, on communication in professional social media (e.g. LinkedIn), in scientific social media (e.g. Research Gate), in general social media (e.g. Facebook) and on the web. Also, the advantages of collaborations between scientific stakeholders and civil society must be disseminated to both communities (scientific and civil).

While some basic principles are common across good practices, the guidelines would mainly need to be classified by type of project. Seven large types of projects were identified, and were grouped according to the timing of their implementation in relation to an infectious disease epidemic: Prevention (before), Epidemic (during), and Aftermath (after). The key messages for each of these seven types of projects are schematised in the below diagram, and also presented in more detail in the guidelines hereafter.

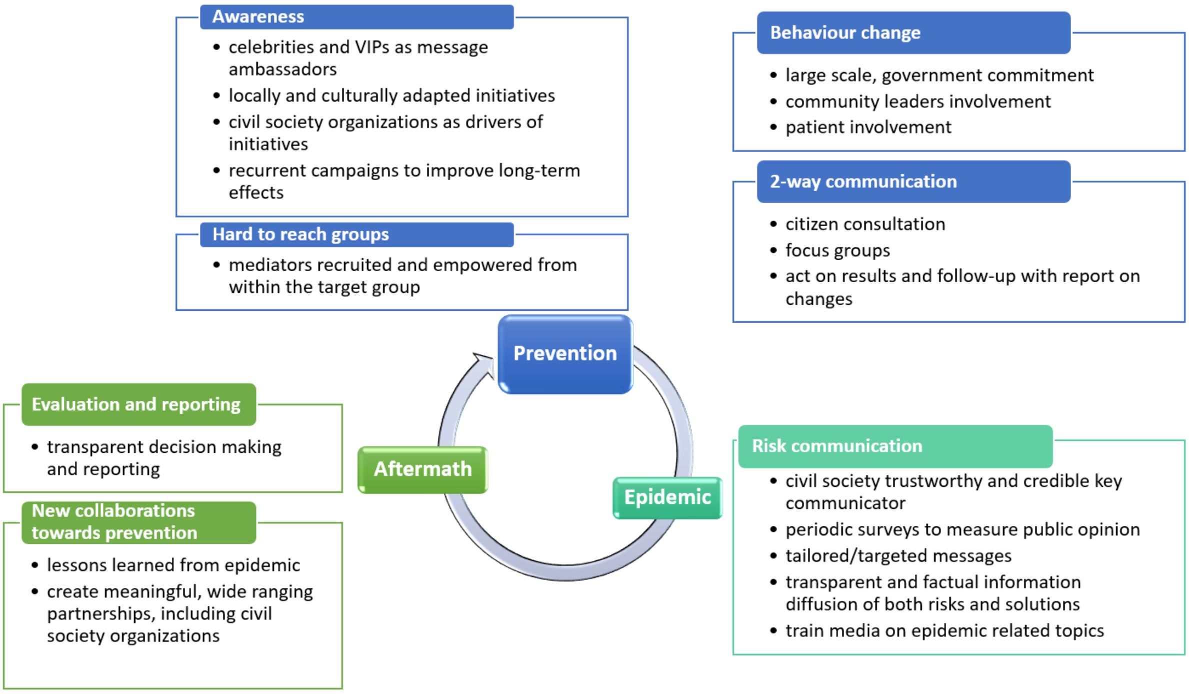


Figure 1. Prevention (before), Epidemic (during), and Aftermath (after): the key messages for each subtype of projects

PREVENTION

2-way communication

- 2-way communication can be effectively achieved through citizen consultations, focus groups, public opinion measuring through periodic surveys
- Members of civil society being consulted should be as heterogeneous as possible, both in their personal health experience and in their socio-cultural background, in order to avoid biases
- Most importantly, results of citizen consultations should be taken into consideration and integrated moving forward with policy and research agendas.
- Provide feedback to citizen on how the results of their participation were used moving forward

Behaviour change

- Attempts at large scale behavioural changes require focused, sustainable and committed involvement from public officials, and institutions
- Community leaders involvement and active support for the messages being diffused is crucial
- Patient involvement and active support is also a key factor of successful behaviour changes

Increasing awareness

- Have celebrities and VIPs as awareness message ambassadors
- Any awareness raising initiative needs to be locally and culturally adapted. Local needs and customs can be identified and understood through focus groups with civil society representatives
- Awareness campaigns have more potential for success if civil society organizations are one of the drivers of the initiative
- Having recurrent awareness raising campaigns can improve long-term effects

Hard to reach groups

- Health mediators, or community workers, are effective at reaching hard to reach groups and providing health and social assistance, and knowledge
- Health mediators, or community workers, are effective when they are recruited from within the target group
- Health mediators, or community workers, should be empowered trained, and provided a stable and remunerated position

EPIDEMIC

Risk communication

- The public needs to be properly informed about the epidemic. The information source should be trusted by the population. Conflicting messages and different information sources are to be avoided, in order to not lose credibility and the public's trust.
- The messages could be transmitted by a civil society trustworthy and credible key communicator
- Periodic surveys can be conducted to regularly keep informed of public opinion
- Thought and research should be invested into designing tailored/targeted messages to different groups of the population, in order to allow people to better identify with the message
- The public needs to be informed in a transparent and informative way of both risks and solutions to the current epidemic
- Training media on infectious diseases and epidemics related topics may lead to improved, clearer, and more informative messages during pandemics / epidemics

AFTERMATH

Evaluation and reporting

- Transparent, clear and complete reports should be presented to the public after an epidemic, with the challenges faced, the measures taken and the effects observed
- Efforts should be made to extract lessons learned from the epidemic in order to move forward towards better preparation for the next epidemic

New collaborations towards prevention

- Identify a need in the fight against infectious diseases, and develop wide ranging partnerships, including civil society organizations, capable of building a project to fill that need

ACTIONS TO AVOID

- "One size fits all" attitude. All initiatives need to be tailored to the targeted population and locally and culturally adapted
- Conflicting, non-transparent, one-way (top-down) communication. Risks should be adequately communicated to the public
- Passive involvement of civil society, as only a receiver of information.

7 The Stakeholder Portal

The Stakeholder Portal (SHP) was conceived as the gateway of the ASSET EU project for interested stakeholders to discuss how to reach a true Public Engagement in Public Health research and the Public Health initiatives concerning Epidemics, Pandemics and their prevention. It should foster discussions among Stakeholders on how to reach best practices in the involvement of Civil Society in these types of projects.

This portal is meant to be an active tool, allowing to spot new patterns, to encourage the evolution of new ideas, to establish a “learning by making” strategy for innovation.

7.1 Organisation of the SHP

The Stakeholder Portal was organized as a multi-social platform with 2 autonomous components:

1. A Facebook group, allowing the SHP to interface with Civil Society.
2. A LinkedIn forum, allowing a constructive dialog with professionals of Public Health and of Industry and Academia.

Initially, we contemplated a third component of the SHP as a part of the ASSET COP; however, due to technical issues (e.g. each member that wished to join the SHP on the COP needed to be internally validated and to be created an ASSET account, etc.), we finally kept only the Facebook and LinkedIn groups, for which there were no connection/membership issues.

This multi-social distribution for the SHP should allow maximizing the participations of the SHs to the Platform. Similarly to the BPP, the number of SHs will have to be dynamic. Of course we will have to make an effort to avoid cancellations from the SHs as well as to minimize registered users with no activity.

Once the SHP was created and invitations were sent, several posts were published in both Facebook and LinkedIn groups under 2 forms:

1. The first and more classical one are debates based on the scientific and operative issues linked to the Good Practices documented in the BPP as well as general aspects concerning SiS for Epidemics and Pandemics. The basis for this type of post is the accumulated interesting materials until now, both in the reports and on the platform. Also, interviews of persons involved in the initiatives described on the BPP were posted in the portals in the hopes of fostering new discussions.
2. Secondly, ideally, once the first posts are published, the next step would be to **cross- fertilize** the themes treated in the BPP and in the whole ASSET **with news and hot themes** spreading on social networks.

Finally, the relationship between BPP and SHP is bidirectional. One aspect, the BPP as source of debate for SHP, has been previously mentioned. Ideally, new Good Practices to be published in the BPP should emerge from the use of the SHP. Due to this bidirectional relationship between the BPP and the SHP, the fact that the number of identified good/promising practices actively involving civil society was limited delayed the start of the SHP.

7.2 List of stakeholders and invitation letter

The preliminary problem of the Stakeholders Portal (SHP) was to find an adequate number of registered SHs, whereas the fundamental issue was to ensure that at least a significant part of them will effectively contribute to the SHP.

It is likely that 1% of the contacted SHs will effectively register and one half of them will really participate to the SHP.

A list of potential stakeholders suggested by all ASSET partners was assembled by ISS. IPRI added its own contribution in order to finalize the list.

Once the list was finalized, an e-mail containing the invitation letter was sent to all people on the list. This invitation letter can be found below:

Email subject: EU Stakeholder Portal on civil society involvement in Public Health Projects – Invitation from the EU Project ASSET

Dear Colleague,

We are contacting you on behalf of the European project ASSET (Action plan on Science in Society related issues in Epidemics and Total pandemics), which aims to improve the preparedness to the threat posed by pandemics (and epidemics) of infectious diseases, by fostering better cooperation between science and civil society and by improving communication channels (http://www.asset-scienceinsociety.eu).

Two increasingly important concepts in Public Health are the "Responsible Research and Innovation" (RRI) and the "Public engagement". Their common aim is that all PH Professionals and Civil Society work actively together during the whole research & innovation process and in practical PH actions "in order to better align both the process and its outcomes with the values, needs and expectations of society". This requires not only open debates, but also the active participation of Civil Society in research and practical PH projects.
https://ec.europa.eu/programmes/horizon2020/en/h2020-section/responsible-research-innovation
http://ec.europa.eu/research/participants/data/ref/h2020/wp/2018-2020/main/h2020-wp1820-swfs_en.pdf

The ASSET project has decided to build a **Stakeholder Portal** where stakeholders, such as yourself, can discuss on these themes and report (if appropriate) their experiences.

We are writing you to invite you to participate (**free of charge**, of course) in our Stakeholder Portal.

The **Stakeholder Portal** exists in two versions: as a LinkedIn group and as a Facebook group, for a larger visibility:

- The LinkedIn group, the “Stakeholder Portal – ASSET Project”, can be accessed at the following link: https://www.linkedin.com/groups/8607721. A LinkedIn account is required, and membership to the group is gained by asking to join the group.
- The Facebook group, the “Stakeholder Portal – ASSET Project”, can be accessed at the following link: https://www.facebook.com/groups/466433323748530/. A Facebook account is required. Anyone can view the discussion threads. In order to start a new discussion or comment on an existing one, membership to the group is required. Membership to the group is gained by asking to join the group.

To give an example, we are interested in fostering discussions among Stakeholders on how to reach best practices in the involvement of Civil Society in these types of projects. Some current good practices are described in the ASSET website in its “Best Practices Platform”: http://www.asset-scienceinsociety.eu/outputs/best-practice-platform.

Should any of your colleagues be potentially interested in registering to the Portal, do not hesitate to share with them this email.

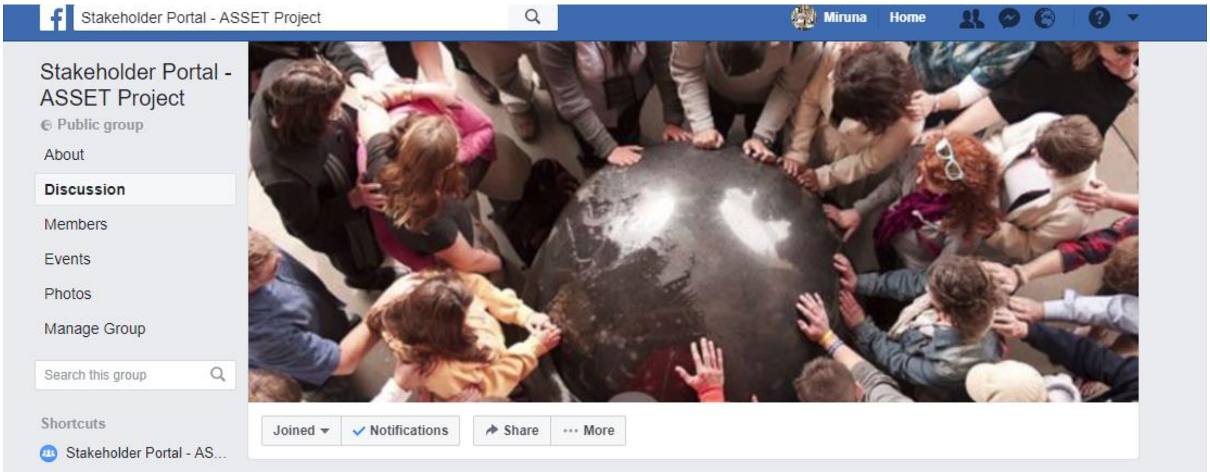
Kind Regards,

7.3 Results

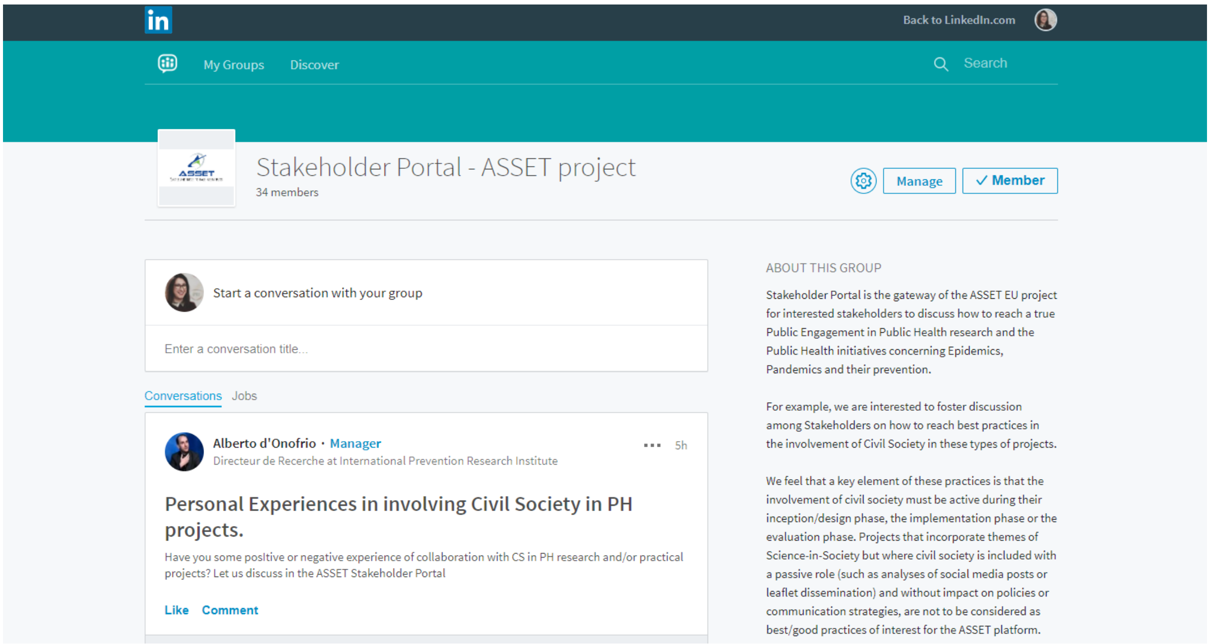
Invitation e-mails to join the Stakeholder Portal were sent to 3553 potentially interested persons.

On the 1st of December 2017, there were 46 and 37 members on the Facebook and LinkedIn groups, respectively, which corresponds to 1% of the contacted persons registered into the SHP.

Even after the project is finished, the Stakeholder Portal will remain active as the legacy of the ASSET European Project.



Screenshot of the SH Portal on Facebook



Stakeholder Portal - ASSET project

34 members

Start a conversation with your group

Enter a conversation title...

Alberto d'Onofrio • Manager

Directeur de Recerche at International Prevention Research Institute

5h

Personal Experiences in involving Civil Society in PH projects.

Have you some posItive or negative experience of collaboration with CS in PH research and/or practical projects? Let us discuss in the ASSET Stakeholder Portal

ABOUT THIS GROUP

Stakeholder Portal is the gateway of the ASSET EU project for interested stakeholders to discuss how to reach a true Public Engagement in Public Health research and the Public Health initiatives concerning Epidemics, Pandemics and their prevention.

For example, we are interested to foster discussion among Stakeholders on how to reach best practices in the involvement of Civil Society in these types of projects.

We feel that a key element of these practices is that the involvement of civil society must be active during their inception/design phase, the implementation phase or the evaluation phase. Projects that incorporate themes of Science-in-Society but where civil society is included with a passive role (such as analyses of social media posts or leaflet dissemination) and without impact on policies or communication strategies, are not to be considered as best/good practices of interest for the ASSET platform.

Screenshot of the SH Portal on LinkedIn

8 Key Messages

The key messages we learnt from the Task are:

- A Best Practice is not only a practice that is replied and used as benchmark but also and mainly a Practice that facilitates mutual learning between Stakeholders and Civil Society that are involved and targeted by it.
- The degree of awareness of the Science with for Society is increasing among SHs, but their willingness of passing from the appreciation of the importance of the subject to real action is insufficient.
- Stakeholders are interested in a collaborative portal and welcome the idea of sharing information and best practices. In practice however, while SH read the posts on the portal, they very rarely contribute with comments or posts of their own.