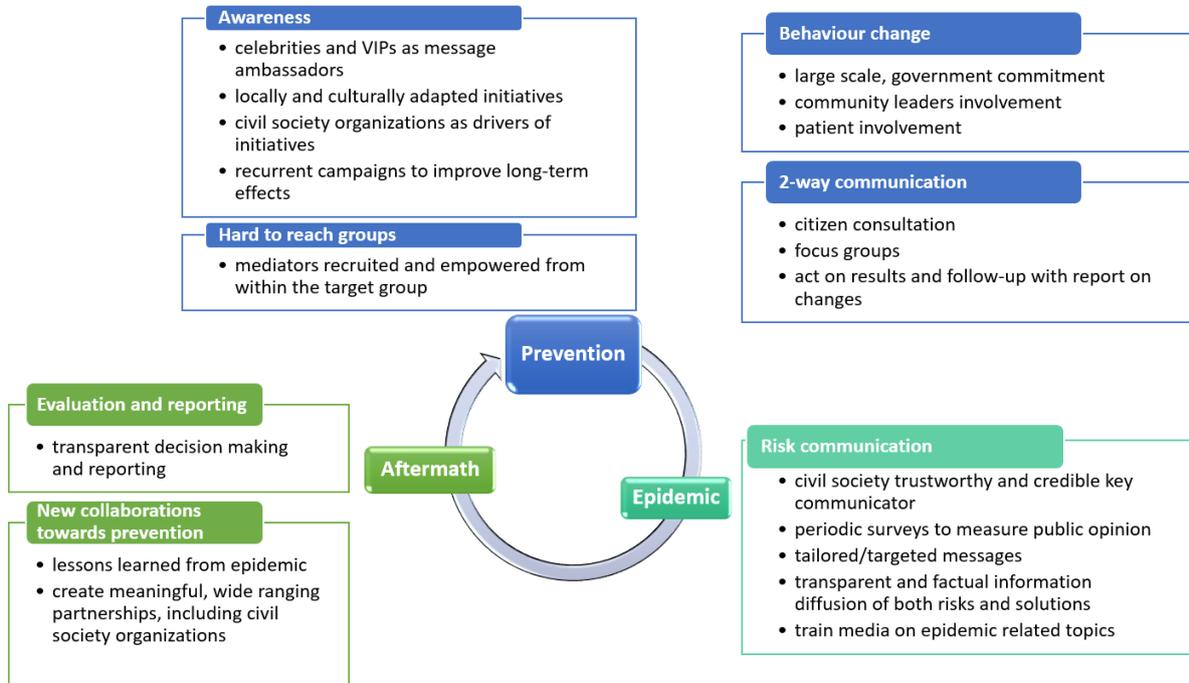




Best Practices Guidelines



A guideline is meant as “Recommended practice that allows some discretion or leeway in its interpretation, implementation, or use.”

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.

Note 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. Some global guidelines were derived from the key messages of the different ASSET tasks:

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 has to be involved in all key phases of a PH research or PH action. In this way, CS representatives will feel 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 (CS) representatives. In 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 SH 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 the 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.

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.

The following guidelines present in synthesized format the key messages derived from the collection of good practices assembled on the portal.

One important aspect that became quickly evident was that there are no “generic” guidelines for civil society involvement. While some basic principles are common across good practices, the guidelines would 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 above diagram, and also presented in more detail in the guidelines hereafter.



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 acted upon moving forward with policy and research agendas.
- Provide feedback to citizen on how the results of their participation were used moving forward
- Civil society partners involved in projects should not feel themselves as guests in the project but as intellectual co-owners.

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.