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WP2 STUDY AND ANALYSIS

D2.3 CRISIS PARTICIPATORY GOVERNANCE

ASSET Project • Grant Agreement N°612236

ASSET

Action plan on Science in Society related issues in Epidemics and
Total Pandemics

7th RTD framework programme

Theme: [SiS.2013.1.2-1 Sis.2013.1.2-1]

Responsible partner: **The International Emergency Management Society**

Contributing partners: **Danish Board of Technology Foundation**

Nature: **Report**

Dissemination: **PU**

Contractual delivery date: **2014-11-31 (m11)**

Submission Date: **2015-03-13 (m15)**

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 612236



co-funded by the EU. GA: 612236

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DOCUMENT MANAGEMENT

PROJECT FULL TITLE	Action plan on Science in Society related issues in Epidemics And Total Pandemics
PROJECT ACRONYM	ASSET
	Coordination and Support Action: project funded under Theme SiS.2013.1.2 "Mobilisation and Mutual Learning (MML) Action Plans"
GRANT AGREEMENT	612236
STARTING DATE	01/01/2014
DURATION	48 months

D2.3 Crisis Participatory Governance Report

Task: T2.3

Leader: The International Emergency Management Society (TIEMS)- Other contributor: Danish Board of Technology Foundation (DBT)

History of changes:

Vn	Status	Date	Organisation / Person responsible	Reason for Change
V1	Draft	2015-02-04	The International Emergency Management Society (TIEMS)/ Kailash Gupta	
V2	Revised Draft	2015-03-10	The International Emergency Management Society (TIEMS)/ Kailash Gupta	1. To strengthen the contribution of the task to set up an effective ASSET MMLAP 2. To include current ongoing 2015 H1N1 outbreak in India as a case study
Vf	Final	2015-03-13	The International Emergency Management Society (TIEMS)/ Kailash Gupta	



Table of Contents

EXECUTIVE SUMMARY	5
Background.....	5
Objectives.....	5
Methods.....	6
Findings.....	6
Conclusions.....	6
1. INTRODUCTION.....	7
2. GOVERNANCE.....	9
3. PARTICIPATORY GOVERNANCE.....	10
3.1 What Participatory Governance Means and Where It Comes From	10
3.2 The Purpose of Participatory Governance.....	12
3.3 Recent Examples of Participatory Governance	13
3.4 Importance, Benefits, and Key Issues and Challenges for Participatory Governance	14
3.5 Methods and Strategies for Participatory Governance	15
3.6 Recommendations to Promote Participatory Governance.....	18
Improving Willingness and Capacity of Citizens / Civil Society Actors.....	18
Improving Willingness and Capacity of State Actors.....	18
Strengthening Bridging Mechanism.....	18
Supporting Enabling Environment.....	19
4. CRISIS PARTICIPATORY GOVERNANCE.....	20
4.1 Framework	21
Resilience and sustainability.....	22
Pre-Crisis.....	23
Crisis.....	23
Post-Crisis.....	25
5. MODELS AND EXPERIENCES.....	27
5.1 Resilience and sustainability.....	27



5.2 Pre-Crisis.....	28
5.3 Crisis.....	28
5.4 Post-Crisis.....	29
 6. KEY ISSUES IN CRISIS PARTICIPATORY GOVERNANCE RELEVANT FOR PANDEMICS.....	31
6.1 Preparedness	31
6.2 Definition	31
6.3 Trust in authorities	32
 7. CONCLUSIONS AND RECOMMENDATIONS FOR THE TASK T2.7 TRANSDISCIPLINARY WORKSHOP.....	33
 Annex 1 - 2011 South Sudan Secession Crisis Case Study.....	35
Annex 2 - 2014 Ebola Epidemic Case Study.....	36
Annex 3 - 2009 H1N1 Pandemic Case Study.....	39
Annex 4 - 2015 H1N1 Outbrek in India.....	43
 BIBLIOGRAPHY.....	46



EXECUTIVE SUMMARY

Background

In epidemics and pandemics rumors and parallel informal information systems have challenged effective risk communication by health workers and authorities, as evidenced, inter-alia, in the current ongoing Ebola epidemic in West Africa and 2015 H1N1 outbreak in India. Research studies have shown that rumors perpetually surface in situations that entail power asymmetries. Such situations often arise when knowledge is contested or is left to a small group of highly technical experts to unravel. Individuals or groups left outside such confined knowledge-hubs often produce their own version of the reality, in effect creating 'rumors'. In the case of the current Ebola epidemic many rumors have flourished. Amongst the most 'popular' is that Western health workers spread the disease, based on American imperialistic visions. This problem has manifested itself as locals hiding sick or dead people. Such rumors constitute parallel information systems which are linked to the application of top-down communication systems and absence of genuine two-way communication systems.

The loss of confidence in international and national health authorities has had a strong impact on vaccination too, affecting not only flu, but also other infectious diseases. Since 2009 rumors and false myths about risks of vaccines have changed attitudes of many families, contributing to reduced immunization rate in some areas, leaving clusters of children unprotected, i.e. against polio, and preventing the achievement of important goals, such as measles eradication from Europe.

Rumors form rapidly during the outbreak of a crisis. Despite efforts by the authorities to deliver correct information, a social reality has arguably already been formed, which rational information is unable to alter. However, whereas rumors are an answer to a call for information from citizens, *Crisis Participatory Governance* practices might answer this call with better information and alter the spread of rumors.

Objectives

The challenges confronting policy-makers and health practitioners' today call for more inclusion of citizens and civil society in risk communication and organized response to epidemic and pandemics threats, in such a way that rumor will not be the main information channel. Pioneering such citizen engagement we have coined the term '*Crisis Participatory Governance*.'

Crisis Participatory Governance starts with effective risk communication that is entirely contingent on successfully identifying the cultural dimensions and priorities of the targeted groups. In doing so, it is critical that the identification is a result of an upstream and downstream, two-way communication process.



Methods

For this report we reviewed the literature on research in participatory governance during crisis, including epidemics and pandemics. We examine aspects of governance at the local, national and international levels for crisis in general, and relate it to infectious disease crisis such as epidemics and pandemics. We discuss crisis participatory governance in the context of case studies including the South Sudan Secession Crisis, the present Ebola epidemic, the 2009 H1N1 pandemic, and 2015 H1N1 outbreak in India.

Findings

We have dissected the Crisis Participatory Governance concept into four overlapping phases of Resilience and Sustainability, Pre-Crisis, Crisis, and Post-Crisis. We have dealt with different crisis participatory governance challenges associated with each phase. For each phase we have identified Crisis Participatory Governance Tools, as depicted in Table 2. We have also discussed models and experiences of recent outbreaks, epidemics, and pandemics in the context of each of the four phases of Crisis Participatory Governance.

Our findings reveal the importance of flexibility in adapting participatory governance activities to different epidemics and to the targeted community. For example during the 2009 H1N1 pandemic, standardized public communications, while factual and useful in some contexts, failed to adequately create understanding of lethality and spread in some areas. A lack of trust in authorities led to rumors, hindering vaccination programs and other health care initiatives.

Conclusions

Good governance is the backbone for equitable and sustained development and effective participation by all people has come to be viewed as a necessary requirement. Participatory governance means including citizens in decision making that has implications for their wellbeing, and transparency in the decision making and implementation processes. This is particularly important during the time of crisis, as people become the center of both providing aid and receiving it. We have developed a model in this report that can guide the use of Crisis Participatory Governance in structuring the four phases of future epidemics and pandemics. However our analysis also shows the critical importance of adapting plans to local conditions through continuous feedback, engaging the public on a day-to-day basis.



1. INTRODUCTION

Action Plan on Science in Society Related Issues in Epidemics and Total Pandemics (ASSET) is a European Union funded Mobilisation and Mutual Learning Action Plans research project being executed by 14 consortium partners, involving 60 researchers from 11 countries during 2014 to 2017. The goals of the project are:

- To forge a transdisciplinary partnership to effectively address epidemics and pandemics
- To explore and map science in society related issues in epidemics and pandemics
- To define and test a participatory and inclusive strategy for successful action
- To identify resources necessary to make the action sustainable after project completion.

ASSET consists of 10 Work Packages and 10 Milestones. One of the 43 Tasks of ASSET is T2.3 Collection and Analysis of Experiences of Participatory Governance in Crisis Management. The deliverable of task T2.3 is this report on Crisis Participatory Governance, which is one of the 59 deliverables of the ASSET project. This report is prepared by The International Emergency Management Society (TIEMS) and The Danish Board of Technology Foundation (DBT). We are pleased to present this analysis of Crisis Participatory Governance, as this is a core element of the ASSET project, intended to alleviate the suffering of citizens from epidemics and pandemics. This report will be available at the ASSET project web site link <http://www.asset-scienceinsociety.eu/outputs/deliverables/crisis-participatory-governance-report>.

In this report we start by explaining the concepts of governance and participatory governance. Participatory governance, according to Wampler and McNulty,¹ “consists of state-sanctioned institutional processes that allow citizens to exercise *voice and vote*, which results in the implementation of public policies that produce some sort of changes in citizens' lives (emphasis in original).” We review the research literature in participatory governance during crisis, and relate it to infectious disease crises such as pandemics. We focus on some key issues in crisis governance relevant to epidemics and pandemics.

We coin and develop “*Crisis Participatory Governance*” as a concept. Crisis Participatory Governance entails including citizens and civil society in risk communication, and an organized response to a crisis so as to engage citizens in policy making and implementation.

Next, we write about the models and experiences of participatory governance practices in times of some recent crisis, starting with South Sudan Secession Crisis, and continue with outbreaks, epidemics, and pandemics including the 2015 H1N1 ongoing outbreak in India, the ongoing Ebola epidemic, and 2009 H1N1 pandemic. Further, we identify key issues in Crisis Participatory Governance relevant to pandemics, and end with conclusions and recommendations for the ASSET task T2.7 Transdisciplinary Workshop, February 24-25, 2015, Geneva. Our recommendation for the Transdisciplinary Workshop centers around

¹ Wampler, B., & McNulty, S. L. (2011). Does participatory governance matter? Exploring the nature and impact of participatory reforms. Washington, DC: Woodrow Wilson International Center for Scholars.



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three issues of resilience: preparedness plans; definition and dissemination about epidemics and pandemics; and creating and sustaining trust among health workers and authorities.



2. GOVERNANCE

While nation-states traditionally have been at the heart of governance, current terminology increasingly applies a more inclusive approach. As a result the notion of governance has become central to the study of political, economic, spatial, and social order².

A diffusion of governance has done away with the narrow equation between government and governance. A remarkable consensus has emerged that the notion of governance far exceeds the concept of government both in scope and scale. The recent success of governance entails that it has different meaning for different people and different fields, to put it mildly.

If one goes into the etymology of the notion of governance, one learns that it is derived from the Latin word '*gubernare*', which denotes the act of steering a ship. *Gubernare* itself is derived from the Greek '*kybernetes*' which today is applied as an analogy for "the art of government" and similarly signifies the steering of a ship³. As such, the etymology supports a broad and inclusive definition of governance.

It must also be said that while the etymology proves that the notion of governance has been around throughout history, it was only as recent as in 1979 – through Oliver Williamson's seminal paper⁴ - that it became popularized⁵.

Today governance is applied and refers to a realm of different fields in different ways: Corporate Governance; Public Governance; Global Governance; Good Governance, and Multi-Level Governance to name a few. Common to most applications though, is the aim of enhancing the effectiveness of authority.

A recent development in governance theory is the emergence of more inclusive approaches. Coined by Joseph M. Bessette⁶ in 1980, the concept of Deliberate Democracy is the foundation of Deliberative Governance, which is equivalent to Participatory Governance.

² From: "Big Government" to "Big Governance"?

³ Verteilte Kontrolle: Institutionelle Steuerung in modernen Gesellschaften.

⁴ Transaction-Cost Economics: The Governance of Contractual Relations

⁵ Between 1975-1980 it accounted for 83% of all scholarly citation of governance

⁶ Deliberative Democracy: The Majority Principle in Republican Government



3. PARTICIPATORY GOVERNANCE

'Participatory governance' denotes a form of governance in which citizens and other non-governmental people and institutions are empowered to use the resources of the State to make decisions about matters that directly concern them. In theory, participatory governance has extensively been dwelled upon.

3.1 What Participatory Governance Means and Where It Comes From

Traditionally, nation-states have been at the heart of governance. Because of increasing concerns over global issues and global actors, global governance - which according to Rosenau and Czempiel⁷ deals with the capacity to enforce decisions on a global scale without a centralized authority - is as a result gaining increased importance.

However, in 1996 Susan Strange⁸ pointed out that the challenges confronting decision-makers today call for new and more inclusive approaches to global governance:

The impersonal forces of world markets, integrated over the postwar period more by private enterprise in finance, industry and trade than by the cooperative decisions of governments, are now more powerful than the states to which ultimate political authority over society and economy is supposed to belong.

In particular, globalization has challenged the reach of nation-states as issues and actors are becoming more global. As such, traditional national policy-making often no longer suffices to address modern policy issues.

Since 1996 though, many new forms of more inclusive governance have emerged to supplement and substitute for such tradition policy-making. Common to most of these new approaches is the inclusion of 'public and stakeholder engagement, collaboration, involvement, and participation'⁹. Within governance theory, such new approaches are grouped and labeled as 'Participatory Governance'¹⁰, as private and public actors are invited center stage in policy-making.

*The political scientist Samuel P. Huntington of Harvard University has suggested that the diffusion of democracy is best understood as three separate waves. **The First wave** was driven by the widening of suffrage (among men) in the early 19th century and 100 years on. **The Second Wave** originated in the end of WWII and lasted until the early 1960s. **The Third Wave**, which still has seen no reversal, was kick-started by the Carnation Revolution in Portugal in 1974 and includes the democratization of Latin America in the 1980s and the former communist countries democratized after the collapse of the Soviet Union. (Democracy's Third Wave. The Journal of Democracy, 2(2))*

⁷ 1992 Governance without Government: Order and Change in World Politics

⁸ The Retreat of the State

⁹ Jacob Schødt's working-paper

¹⁰ Some branches of academia refer to it as 'Collaborative Governance'.



The emergence of Participatory Governance practices is by no means confined to supranational institutions. The Third Wave of Democratization (See Text Box on p. 10) led to an increased decentralization of regulation, not only in new democracies, but also in more mature democracies as well.

As with most political concepts, 'Participatory Governance' has never enjoyed a single uncontested definition. Jenny Stewart,¹¹ Professor of Public Policy, has defined it in the following way:

Participatory governance' denotes forms of governance in which non-governmental actors (usually 'citizens') are empowered to use the resources of the State to make decisions about matters that directly concern them.

Participatory governance, according to Wampler and McNulty¹², "consists of state-sanctioned institutional processes that allow citizens to exercise *voice* and *vote*, which results in the implementation of public policies that produce some sort of changes in citizens' lives (emphasis in original)." While the semantics differ between academics and institutions, the empowerment of citizens or organizations is central to most definitions. Accordingly, the UN's¹³ core emphasis is put on effective participation:

We define 'effective' participation as one in which all the relevant stakeholders take part in decision-making processes and are also able to influence the decisions in the sense that at the end of the decision-making process all parties feel that their views and interests have been given due consideration even if they are not always able to have their way.

Paradigmatic case study #1:

What New Orleans is for Jazz, Porto Alegre is for Participatory Governance. Rooted in Brazil's democratization in the late 1980s, one of the most successful and best-documented experiments in Participatory Governance in the modern world emerged. In an alliance between civil society and the then oppositional parties, methods to incorporate citizens' participation in governance was formed and institutionalized. In Porto Alegre, the forms and procedures we today know as participatory budgeting was established in 1989. Moving beyond public hearings and dualistic framed votes insofar the decision-making is a yearlong process. Citizens negotiate between themselves and with government officials over the allocation of public resources. When agreement is reached the implementation is subject to oversight by a citizen-based committee. (Does PG Matter 2011)

Despite the different semantics used to define Participatory Governance, there seems to be consensus that the defining feature is the inclusion of non-state actors in decision-making within public agencies. However, a disagreement still remains on the extent to which Participatory Governance should include all non-governmental actors, or whether it should be limited to strictly involving citizens' participation. (A disagreement Professor Stewart's definition elegantly captures above.)

¹¹ The Dilemmas of Engagement: The Role of Consultation in Governance

¹² Wampler, B., & McNulty, S. L. (2011). Does participatory governance matter? Exploring the nature and impact of participatory reforms. Washington, DC: Woodrow Wilson International Center for Scholars.

¹³ Participatory Governance and the Millennium Development Goals (MDGs)



However, as shall be demonstrated later, there is no blueprint for Participatory Governance, as the process is contingent on local conditions including culture, institutional organization, etc. The literature reflects this by pointing to the importance of incorporating such local settings, rather than uncritically applying best practices¹⁴.

3.2 The Purpose of Participatory Governance

Having introduced what Participatory Governance means and where it comes from, it is only natural to continue with a discussion of the purpose of Participatory Governance. Participatory Governance has both in theory and practice been linked to a process of democratization of policy-making. For that reason, it has been advanced as a response to the 'democratic deficit'¹⁵ to which modern political systems are often attributed.

Throughout the last two decades, the demand for more non-state participation in policy-making has increasingly been met in various policy issues. While Participatory Governance has traditionally been the purview of development policy and studies, it is currently gaining a foothold in policy areas monopolized by scientific experts. Hence, Participatory Governance is diffusing into science and technology decision-making, and within social science and biotechnology, leading to considerations of Crisis Participatory Governance.

Before advancing this further, an examination of the rationale underlying participatory procedures and practices will be elaborated.

Arguably, there are as many conceptualizations of the motives underlying Participatory Governance as there are publications within this field. However, Innes and Booher¹⁶ have suggested that five distinct reasons can be underlined, which include most of the core claims made when highlighting the merits of participatory procedures and practices:

- As the public's opinion is presented to policy-makers, the policy-makers can improve their basis for decision-making
- Local information is increasingly essential for policy makers as governance systems expand and consequently become more distant from its constituencies
- By enabling participation of less influential groups, fairness and justice is arguably promoted. There are many theories and examples of how vested interest influences policy – participatory practices are seen as an important countervailing force
- The legitimacy of political decision-making is strengthened as more voices are heard. The typical example of this is public hearings, common at all levels of national political decision-making

¹⁴ Participatory Governance: The Missing Link for Poverty Reduction

¹⁵ Participatory Governance: From Theory To Practice

¹⁶ 2004 Reframing Public Participation: Strategies for the 21st Century



- Participatory Governance is often applied in accordance with the rule of law, also illustrated by public hearings.

While other articles and reports¹⁷ offer different conceptualizations of the underlying reasoning and motivation behind Participatory Governance, the five bullet points above capture the essence of the debate quite well.

However, Participatory Governance procedures are still in their nascent phase. The merits of reducing the 'democratic deficit' within political systems are entirely contingent on how Participatory Governance procedures are linked to their political systems. Unfortunately such linkages still differ on a case-by-case basis; from country-to-country and from constituency-to-constituency. As a result, some procedures are still not fully utilized and arguably have limited impact on policy making. In a 2007 survey by CIVICUS: World Alliance for Citizen Participation, only 12% of respondents considered the 'impact/success' of their current Participatory Governance initiative as 'very good,' while 41% rated them as 'okay,' and 39% as 'limited'¹⁸.

3.3 Recent Examples of Participatory Governance

Examples from the industrialized world, in particular Europe, involve the use of participatory methods in order to introduce labor market reforms and improve competitiveness while maintaining social peace.¹⁹ In the "developing" world, South Africa provides an excellent illustration of this trend, since it is the only country in the world to have institutionalized to a high degree the presence of civil society groups in the public policy-making process at the national level. At the community level, many examples of participatory democracy have mushroomed since the early 1990s, in both the industrialized and the "developing" world. The Porto Alegre (Brazil) participatory budgeting process often figures as the most prominent and successful participatory initiative at this level.²⁰

At the regional level, the European Union is a prime example of participatory approaches to social policy. Besides the EU, the newly formed African Union also stands out for the extent to which it intends to integrate civil society in its permanent organs which deal with socio-economic issues. At the international level, the discourse of participatory governance has been around for quite a long time in international instruments. Interestingly, many international agreements concerning the provision of financial resources, the financing of development projects, and the liberalization of trade require guarantees of good governance.

¹⁷ Citizen Involvement in Public Policymaking: Does it Improve Democratic Legitimacy and Accountability? The Case of pTA

¹⁸ Strategies for Promoting Participatory Governance: A Multi-Stakeholder Brainstorming Workshop

¹⁹ Socially sustainable development and participatory, Ishikawa, 2003; Compston, 2002, Retrieved from http://www.ilo.org/wcmsp5/groups/public/---dgreports/---inst/documents/publication/wcms_193610.pdf

²⁰ Voice and Vote: Decentralization and Participation in Post-Fujimori Peru, Grey and Sintomer, 2002. Retrieved from Google books



In the developed world too, people's participation in social decision-making processes is increasingly being emphasized as a means of combating a range of social malaise, including the problems of social exclusion, political apathy and so on. Finally, in post-conflict, post-transition and other fragile societies, broad-based participation in public affairs is being promoted as a means of creating the social capital necessary for building a cohesive society.²¹

3.4 Importance, Benefits, and Key Issues and Challenges for Participatory Governance

In view of above, we advance with a discussion on the importance and benefits of Participatory Governance as well as its key issues and challenges.

While the importance of Participatory Governance has some overlap with the purposes discussed above, additional benefits will be highlighted hereunder:

- Service delivery is improved
- Citizens are empowered
- Government's monopoly on policy-making is reduced.

Before moving ahead with the key issues for Participatory Governance, a few comments should be attached to the bullet points.

First, in areas such as health care, education and development policy there is no lack of case-based evidence of Participatory Governance's effectiveness. A central feature often emphasized is that it is believed to lead to quicker responses to emerging issues and problems²². Thus, by incorporating local knowledge and expertise in the design and development of solutions, more effective responses and service delivery are achieved.

Second, conventionally, ways to improve public access to information about decision-making have been seen as the best way to include citizens and non-governmental organizations (NGOs) in policy-making. Participatory Governance moved beyond this and claims to support citizen competence and local community-building by developing citizens' communicative skills. Following the human rights-based approach, it is argued that participations lead to a higher human development.

Third and final, solutions to policy issues are today often beyond the reach of single nation-states. Global issues call for global governance, and recently it has been well established that problems are becoming

²¹ Participatory Governance and the Millennium Development Goals, United Nations, Retrieved from <http://unpan1.un.org/intradoc/groups/public/documents/un/unpan028359.pdf>

²² Frank Fischer (2012) Participatory Governance: From Theory To Practice



more and more integrated and complicated, calling for competences beyond the scope of nation-states. The systematic inclusion of civil society among major organizations such as the UN, the EU, and the World Bank demonstrates this.

Just as important as reflecting on the benefits - to say the least - is to reflect on the key issues and challenges confronting Participatory Governance. Listed below are three categories that encompass the quintessential challenges confronting Participatory Governance:

- Governance cycle
- Citizen competence
- Bridging instruments.

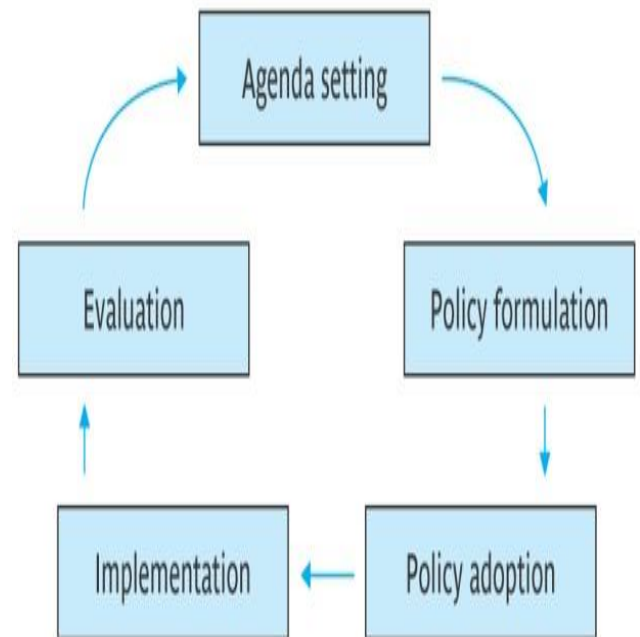


Figure 1: The Traditional Governance Cycle

First, the classical perception of linear policy-making illustrated by the governance cycle (Fig. 1) is challenged at all levels of governance. Numerous empirical examples suggest that *de facto* policy-making is not linear, but rather more stochastic. Hence, there is a need for strong participation at all stages of the policy-making and not only in final public hearing. Second, Participatory Governance has no relevance if citizens and organizations are not empowered or capable to participate. While middle-class citizens or well organized, NGOs are well equipped to meet the demands of participation, marginalized groups and community-based organizations are in dire need of empowerment. Third and final, Participatory Governance's effectiveness is entirely contingent on its linkages to the political systems. Without the right interface between the state and non-state actors, such linkages will stop short fostering *effective* participation.

3.5 Methods and Strategies for Participatory Governance

Political systems and civil society are by no means homogeneous entities, and differentiation is essential for successfully applying the concepts. Disaggregation and discrepancy is hence imperative when it comes to governance structures with the purpose of developing an effective interface for participation, i.e. developing methods and strategies for Participatory Governance.

Nevertheless as argued above, no blueprint for Participatory Governance could be deduced, as effective implementation is contingent on local conditions and structures. Further, it is argued among practitioners that Participatory Governance is more a political tool than a technical program. As the success of Participatory Governance schemes is contingent on local institutions, widespread applications of 'Best

Practices' are not advisable, however following The Woodrow Wilson International Center for Scholars²³ 'Best Guiding Principles' is another matter. Professor Paul DiMaggio of Princeton University, an expert in 'Institutional Entrepreneurship', suggests that the genesis of new institutions, as Participatory Governance practices, arises based on (resourceful) actors' agency. The two paradigmatic case studies in Text Box 1 (page 11) and 2 (page 17) give warrant to this claim.

In a 2007 workshop hosted by CIVICUS: World Alliance for Citizen Participation, the following figure (Figure 2) conceptualized the institutional factors affecting Participatory Governance. To some extent, some of these factors have already been examined above. Hence, only a brief summary of the enabling environment and willingness and capacity of the citizens and state will follow. We explain the bridging mechanisms, which are the fundamental methods for Participatory Governance.

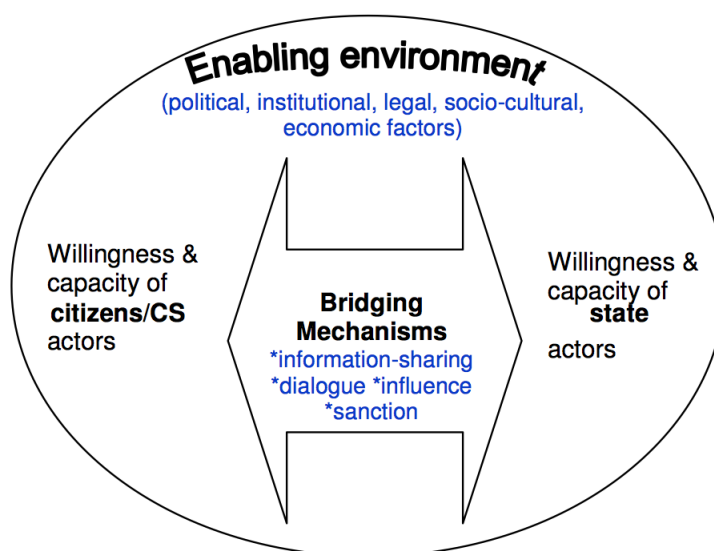


Figure 2: Factors Influencing Participatory Governance (Civicus 2007)

There is no clear link between how advanced an economy is and the success of Participatory Governance. Rather, it seems to be empirically linked to progressive political parties (as discussed in the two paradigmatic case studies). It goes without saying that democratic practices, all other things being equal, struggle in authoritarian regimes, but some of the most memorable projects are embedded in young democracies.

The willingness and capacity of citizens and civil society to participate is obviously the most decisive factor for Participatory Governance. Previously, we described that empowerment of marginalized groups in society, i.e. women, ultra-poor and some ethnic groups, and community-based organizations is central to the capacity of participation. An aspect that has yet to be developed is the cost of participation. From economics we know that all action has an opportunity cost (the cost of sacrificing an alternative in order to pursue a certain action), as such it is crucial to mediate such costs.

²³ Does Participatory Governance Matter?: Exploring the Nature and Impact of Participatory Reforms (2011)



The willingness and capacity of the political system is equally important to Participatory Governance. As the paradigmatic case studies testify, political parties are often the driver in that process. Furthermore, American research suggests that only involving citizens in mandatory public hearings is counterproductive, as effective influence is rare, despite the fact that citizens' are lured by such promise.

This brings us to the core of Participatory Governance: The mechanisms bridging the political systems and citizens. The dynamics of such mechanisms are both sequential and stratified, i.e. the dynamics vary according to the stages in the governance cycle (sequential) and according to which level of governance is being dealt with (stratified).

One conceptualization of such relations could be borrowed from the 2006 concept note of CIVICUS Participatory Governance program, depicted in Table 1 below:

	National level	Local level
Agenda-setting and policy- making	Deliberative polling, citizens' juries, participatory policy-making	Participatory development planning
Revenues	Public revenue reporting	Participatory tax collection
Budget formulation	Independent budget analysis, alternative budgets	Participatory budgeting
Public expenditures	Participatory expenditure tracking surveys	Public posting and reporting of local expenditures
Public services	Citizen evaluation of public services (e.g. citizen report cards)	Participatory M&E of services (e.g. community scorecards)
Public oversight	Civil society-ombudsman intermediation	Citizen oversight committees

Table 1: Sequential and Stratified Participatory Governance (CIVICUS 2006²⁴)

²⁴ http://www.civicus.org/downloads/pg/PG_Annex6_ConceptNote.pdf

Paradigmatic case study #2: Within the world's largest democracy, India, another famous Participatory Governance case study is embedded in the state of Kerala. Already in 1992 constitutional amendments aimed at decentralizing governance and boost participatory governance, however not until 1996, with the Left Democratic Front winning power in the state of Kerala was the policy putted into practice. Kerala has since moved on to become the showcase of participatory planning for local



The two case studies described in the text boxes above respectively deal with participatory development planning and participatory budgeting. Further empirical examples could be highlighted if the scope of the report had allowed for it.

3.6 Recommendations to Promote Participatory Governance

The essence of the ASSET project is mobilization and mutual learning action plan in order to improve pandemic preparations. We need to include in our future plans of action sound activities to mobilize citizens and stakeholders and promote mobilization and mutual learning. Based on the model presented in Figure 2, our recommendations to promote participatory governance are as follows.

Improving Willingness and Capacity of Citizens / Civil Society Actors

We recommend that to improve willingness and capacity of citizens and civil society actors to participate in governance they need to be empowered. In general this is applicable for all citizens and civil society actors, but particularly for marginalized groups in society, i.e. women, ultra-poor, illiterate, physically and psychologically challenged, with lower social capital, and some ethnic groups. But the question is how to empower them in participatory governance, and why they would participate when they have higher priorities, for example of hand-to-mouth existence. This question is worth further research. Our preliminary hypothesis is that if the marginalized groups are given financial and non-financial incentives they may be motivated for participatory governance. Financial incentives could be in the form of payments for their time in participatory governance activities. Non-financial incentives could be appointing some of them leaders, a T-Shirt or a jacket proclaiming their position in society, certificates, and awards for work in participatory governance.

Improving Willingness and Capacity of State Actors

It is difficult to give general recommendations to improve willingness and capacity of state actor in participatory governance since it is a matter of culture, tradition, religion, legacy, and existing practices. We consider state actors as elected politicians and nominated or appointed civil servants. Free and fair elections and right to re-call along with higher percentage of voting and voter education may help in participatory governance. But elections happen after few years. State actors willingness and capacity to improve participatory governance could be improved if their effective legal systems for them, transparency in operation of their duties, and almost full disclosure of sources and utilization of finances. The print and social media could also help by deep rooted investigating journalism and exposing wrong deeds of state actors.

Strengthening Bridging Mechanism

There are three recommendations for bridging political systems and citizens to improve participatory governance as depicted in Figure 2. First, the political system needs to be transparent and share most of the information with the citizens. This is already covered above, but these are cross-cutting and



overlapping concepts. Second, there need to be open dialogue between political systems and citizens. The dialogue should not be a mere eye wash and controlled. The dialogue need to be genuine moderated by a representative of citizens, not political system, and the voice and vote of citizens should get precedence in decision making. Third, citizens should be able to influence most of the decisions. Fourth and last, citizens should be able to sanction the political system if the decisions taken are not effectively implemented and there is financial corruption or time delays in implementation of projects or daily routine citizen activities.

Supporting Enabling Environment

Our recommendation for promoting participatory governance by supporting enabling environment hover around five items depicted in Figure 2. First and most important is that the political system need to be supporting an enabling environment for participatory governance. Second, there need to be intuitional mechanisms through which citizens could participate in governance. In this regard we recommend use of policy informatics (different from information policy). Erik W. Johnston, the Director of the Center for Policy Informatics at Arizona State University in just released (March 1, 2015) edited book²⁵ defines, “policy informatics is the study of how computation and communication technology is leveraged to understand and address complex public policy and administration problems and realize innovations in governance processes and institutions (p. 3). Third, legal systems that is laws, rules, and regulations need to be in place for citizens to participate in governance. One example is the protection of whistle blowers. Fourth, socio-cultural factors should be created for an enabling environment for participatory governance. This is vast area and needs further research for coming out with specific recommendations. Fifth, economic factors need to be taken into account to promote participatory governance. We have already mentioned about giving financial incentives to the citizens for participatory governance related activities.

²⁵ Johnston, E. W. (2015). Governance in the information era: Theory and practice of policy informatics. New York: Routledge



4. CRISIS PARTICIPATORY GOVERNANCE

With the diffusion of Participatory Governance into the policy areas requiring the most expertise, dominated - not to say monopolized, by elites - the frontiers of for Participatory Governance are currently expanding. As such, this report suggests pioneering biotechnology, crisis handling, and epidemic management by the implementation of Participatory Governance practices.

The introduction of social media and cellular phones (amongst other ICTs) even to the most fragile regions in the world has proven to be both an opportunity and a challenge for risk communication. This is illustrated by the case study of South Sudan Succession Crisis given in Annex 1. Another example is Switzerland, which has a lot of laws already in place for participatory governance. They in fact take a poll on the percentage of tax to be levied on them. In particular through the recent outbreak of Ebola in West Africa (See Figure 3), rumors and parallel informal information systems have challenged effective risk communication by the authorities. For an Ebola epidemic case study, please see Annex 2.

A series of well-documented studies has shown that rumors perpetually surface in situations that entail power asymmetries²⁶. Such situations often arise when knowledge is contested or is left to a small group of highly technical experts to unravel. Individuals or groups left outside such confined knowledge-hubs often produce their own version of the reality, in effect creating 'rumors'. Clara Barrelet and her colleagues argue that such rumors constitute parallel information systems and link their introduction to the application of top-down communication systems.



Figure 3: Ebola in West-Africa.

As such, the challenges confronting policy-makers and health practitioners' today calls for more inclusion of citizens and civil society in risk communication and organized response to pandemics threats, in such a way those rumors will not be the main information channel. Pioneering such citizen engagement we have coined the term '*Crisis Participatory Governance*.' Examining the existing literature, it became clear that Crisis Participatory Governance is a new concept. Neither at Google Scholar nor through a regular Google search with the phrase "Crisis Participatory Governance" produces any useful hits. The existing literature within Participatory Governance and risk communication incorporates each other only sporadically.

Effective risk communication is entirely contingent on successfully identifying the cultural dimensions and priorities of the targeted groups. In doing so, it is critical that the identification is a result of an upstream

²⁶ Barrelet et al. (2013) refer to three distinct peer-reviewed articles.



and downstream, that is two-way communication process. For a detailed discussion on risk communication, see Chapter 5 Critical Issues Concerning Risk Communication during Epidemics/ Pandemics/ Endemics of D2.2 Reference Guide of Unsolved Scientific Questions Related to Pandemics and Epidemics, which will be available at <http://www.asset-scienceinsociety.eu/outputs/deliverables/reference-guide-scientific-questions>.

While the challenges associated with specific bridging mechanisms at different levels of the policy-cycle have been discussed, other challenges are specific to crisis participatory governance. One of which is that the effective communication of biosecurity is constrained by the prevalence of communication practices that *de facto* portray laypersons as ignorant recipients of expert knowledge²⁷.

Hitherto the focus has been on empowerment and engagement of citizens. However recent research suggests that if policy-makers and health practitioners are not ready to genuinely engage in effective participation and modify their assumptions, crisis participatory governance is not worthwhile. However, contemporary American case studies suggest that authorities actually are willing to do exactly that²⁸.

4.1 Framework

Related to Crisis Participatory Governance is the related United Nations Development Program (UNDP)'s term 'Crisis Governance'. Its conceptualization of the crisis term is much related to ours, as they recognize that the concept is sequential and relief should be designed accordingly. Empirically, however, most of UNDP's work center on conflict-situations and its effects on human development. Though a noble cause, this is not the focus we wish to pursue.

As a concept 'crisis' has never enjoyed an uncontested meaning or application²⁹, however, today it is widely accepted that a crisis is multifaceted and longitudinal phenomenon. Consequently, effective crisis response, communication and preparation are by no means confined to the actual crisis. Rather it is a

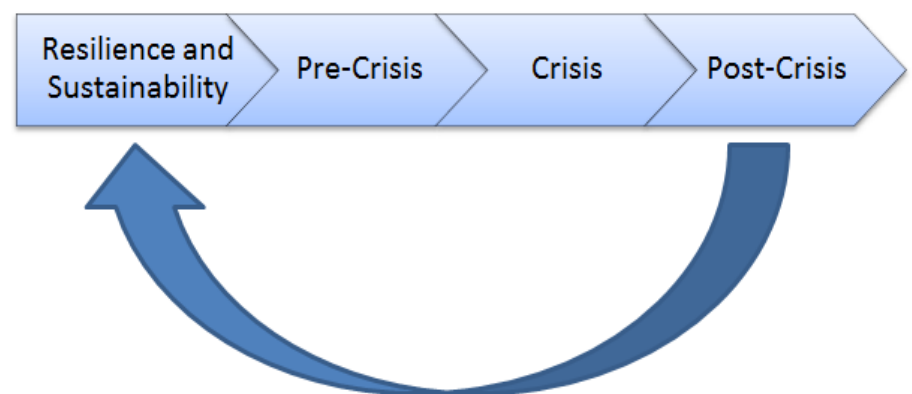


Figure 4: Phases of Crises Participatory Governance

²⁷ Barrelet et al. (2013)

²⁸ Biosecurity risk and peri-urban landholders – using a stakeholder consultative approach to build a risk communication strategy

²⁹ Often the Oxford English Dictionary's (1992) definition is used as a baseline: "A situation that is perceived as difficult. Its greatest value is that it implies the possibility of an insidious process that cannot be defined in time, and that even spatially can recognize different layers/levels of intensity. A crisis may not be evident, and it demands analysis to be recognized. Conceptually, it can cover both preparedness and response ("crisis management")"



sequential process involving several overlapping phases (See Figure 4). By understating crisis through several phases one is analytically more capable of dissecting the different crisis participatory governance challenges associated with the respective phases, which is crucial to fully utilizing the potential of the concept.

In the following we will briefly discuss each phase, and relate it to its particular crisis participatory governance tasks.

Resilience and sustainability

Resilience and sustainability is central to minimizing the costs of a crisis. The underlying reasoning is that vulnerability is reduced by building sustainable and resilient systems. Consequently, the impact of a crisis is minimized.

Disasters since 1982

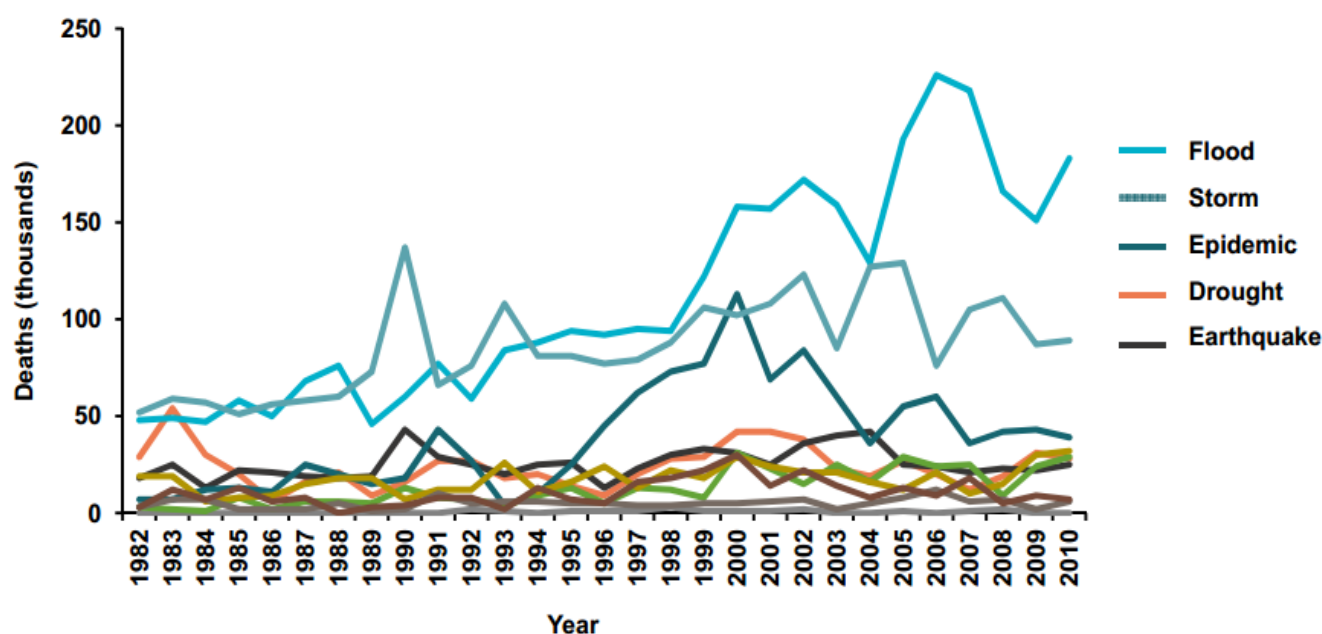


Figure 5: Source: The Institution of Civil Engineers 9th Brunel International Lecture Series

As Figure 5 suggests, crisis as epidemics or pandemics are a fact of life. However, while we cannot prevent an outbreak or a hazard, we can through resilient systems³⁰ control or minimize its impact.

Although, there is no one way of building resilient systems, we suggest that Participatory Governance holds a great potential in this regard. As trust is essential for effective risk communication, and there has

³⁰ Resilience is the ability of a system to withstand shocks and stresses while still maintaining its essential functions. Resilient systems are also better able to repair and recover afterwards (The Institution of Civil Engineers 9th Brunel International Lecture Series).



been a decline in the trust of the state, international institutions, and pharmaceutical companies, Participatory Governance practices should aim at restoring such trust.

Crisis Participatory Governance tools in resilience and sustainability³¹:

- Participatory planning
- Citizens' evaluation of systems

At this stage of the 'crisis-cycle' the emphasis should be put on building resilient systems, e.g. public health emergency response guides. As such, guidelines provide the basis for an organized response. In this process citizens and civil society can contribute with participation in the planning and hearing of such responses and perhaps evaluation.

Pre-Crisis

Pre-Crisis is the phase in which an immediate threat has been identified, and is likely to affect a given society. Examples span from a tsunami warning to the outbreak of an infectious disease in a neighboring area.

Critical to this phase is the mobilization of citizens and civil society to support institutional actors' mitigation of the effects. Such an inclusion in the early crisis response helps identify the needs of communities in an upstream process, rather than decentralizing through a top-down approach.

Quote:
Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.
—Margaret Mead

Crisis Participatory Governance tools in Pre-Crisis:

- Participatory crisis response
- Participatory information
- Participatory evacuation / isolation planning
- Participatory exercises.

At this stage the critical crisis participatory governance tools center on effective risk communication, presumably by institutional actors. They may engage citizens and effectively communicate which pivotal precautions that must be in place to reduce casualties. Examples include information campaigns in the case of the current outbreak of Ebola, or vaccination-campaigns in the case of 2009 H1N1 pandemic (H1N1 case study is in Annex 3).

Crisis

Crisis is the stage where the difficulty peaks. It could be the outbreak of an infectious disease or an impact of a catastrophe. Only resilient systems can withstand the pressure from a crisis. The recent outbreak of

³¹ This is not an exhausted list; rather it is the quintessential tools applied at this phase.

Ebola in West Africa has led to civil unrest and violence against aid workers. The public health infrastructure of Liberia has *de facto* vanished, which shows the need for a resilient system.

At this stage citizen participation is helpful. Figure 6 depicts Red Cross volunteers in Guinea travelling door-to-door to raise awareness and share preventative information about Ebola.



Figure 6: Red Cross volunteers in Guinea travel door-to-door to raise awareness and share preventative information about Ebola.

During the outbreak of a crisis rumors form rapidly. Despite efforts by the authorities to deliver correct information, a social reality has arguably already been formed, which rational information is unable to alter³². This is also evident from the currently ongoing 2015 H1N1 outbreak in India, in which 1,401 persons have died and 25,681 persons affected in 2015 till March 8. The number of deaths in 67 days this year is nearly 6.5 times the whole of 2014 or more than any year since 2011. Even the number of affected people are nearly five times of the whole years since 2011 (Annex 4). However, whereas rumors answer to a call for information from citizens, crisis participatory governance practices might help alter the spread.

Crisis Participatory Governance tools during Crisis:

- Participatory information sharing
- Participatory health care /service provision
- Participatory crisis response

³² Kaler , A. (2009) 'Health interventions and the persistence of rumor: the circulation of sterility stories in African public health campaigns', *Soc Sci Med*, 68:1711–1719.



- Participatory humanitarian aid.

The tools and practices applied at this stage should aim at mitigating the harm to the least possible effect. Door-to-door information campaigns have been widely applied during crisis times. Due to the contagious nature of the Ebola virus, the handling of possible infected persons needs to be subject to the strictest precautions. Such precautions are pivotal to the spread of contamination. However, the prevalence of rumors (sometimes bordering on conspiracy theory) hinders such handling. By providing door-to-door information by fellow citizens, one can to some extent countervail such distrust.

Post-Crisis

Post-Crisis is the last stage we describe. This phase is much related to the resilience and sustainability phase, which is illustrated by the arrow in Figure 4. It primarily deals with the learning and evaluation.

In the wake of a pandemic or comparable disaster there is always room for learning through evaluations and analysis. In recent times new tools have been developed to facilitate such a process. Hurricane Sandy was the popular breakthrough of 'Big Data' learning. 'Big Data' long has been reckoned to hold important merits in the pre-crisis level. However, Direct Relief - a private humanitarian nonprofit organization based in Santa Barbara, California - used 'Big Data' to map open shelters and undamaged pharmaceuticals, to effectively target the relief is an example worth emulation.

Crisis Participatory Governance tools Post-Crisis:

- Participatory workshop evaluation
- Stakeholder surveys
- Citizen report cards
- Participatory planning.

Essential for the crisis participatory governance tools applied here is to derive knowledge in order to build more resilient systems, as symbolized by the arrow completing the cycle of Figure 4.

The development of the tools listed above in recent crises has shown that through participatory evaluation tools, such as citizens' report cards and surveys, one can derive such knowledge. By using this knowledge with a tool from the first phase, participatory planning can be an elegant bridging mechanism to complete the cycle.

'Crisis governance' and 'risk communication' are related terms and are well established conceptualizations. However, by including citizens and civil society we hope to establish a convergence between science and society, which we posit is more practical for the benefit of society.

In conclusion, crisis participatory governance is emerging since citizens are no longer passive recipients of knowledge generated by 'experts' or professionals. Rather they are a valuable source of information in



every respect. Utilizing that knowledge in an upstream process is vital for institutional actors responding to a crisis. The table below does not contain an exhaustive list; nevertheless, it is a start and should be used as a source of inspiration for further research and development.

The Table 2 below provides the visual summary of the suggested crisis participatory governance tools.

Phase =>	Resilience	Pre-crisis	Crisis	Post-crisis
Crisis Participatory Governance tools	Participatory planning	Participatory crisis response	Participatory information sharing	Participatory workshop evaluations
	Citizens' evaluation of systems	Participatory information	Participatory health care /service provision	Stakeholder surveys
		Participatory evacuation / isolation planning	Participatory crisis response	Citizen report cards
		Participatory exercises	Participatory humanitarian aid	Participatory planning

Table 2: Summary of crisis participatory governance tools.



5. MODELS AND EXPERIENCES

Based on the crisis participatory governance framework developed and depicted in in Table 2, we analyze models and experiences of participatory governance practices in times of crisis.

5.1 Resilience and sustainability

The 2009 H1N1 pandemic experience demonstrated issues that can arise when there is a lack of participatory governance in the planning and preparations for a crisis. Experience with previous SARS and avian flu crisis had led to enhancements in International Health Regulations by the World Health Organization (WHO), and in Europe influenza preparedness plans were a focus of attention for the European Commission, the WHO European Office, and the European Centre for Disease Prevention and Control. Much of the world felt well-prepared for a severe influenza outbreak.³³

As the H1N1 pandemic unfolded, it became clear that the world was not as well-prepared as was widely believed. The carefully crafted plans did not adapt well to the specifics of the H1N1 situation. For example, definition of pandemic phases of WHO was not a good fit to the widely spreading but relatively mild H1N1 influenza. WHO communications based on their definitions promoted panic instead of reasonable action.

In addition to lack of flexibility, planning based on previous pandemics failed to address factors that turned out to be critical to the H1N1 response. Failure to deal adequately with the complexities of multi-national/multi-stakeholder resource allocation resulted in late production of vaccine doses and shortages where doses were needed most. This in turn fueled public mistrust of authorities and pharmaceutical companies. Planning also failed to take into account the revolutionary impact modern information sources and communication technologies, such as social media, have on the general public.³⁴

Planning for H1N1 miscast civil society as vulnerable parties in need, waiting to be educated and led. While this reflects a noble sentiment, it underestimates the modern citizens' need and capacity to see and choose for themselves, and the increasing role individual choice plays in health outcomes.³⁵

The increasing interdependence and complexity of our world also works against planning without accounting for all important stakeholders, public, commercial, and institutional. Even within the particular domain of science, H1N1 preparation has been criticized for not including social scientists to work with doctors, epidemiologists, etc.³⁶ The same is continuing in the currently ongoing 2015 H1N1 outbreak in India (Annex 4).

³³ HEG Expert Group (2011)

³⁴ IBID

³⁵ Kickbusch (2014)

³⁶ HEG Expert Group (2011)



Greater participation of citizens and all stakeholders during pandemic preparation would likely have improved the outcomes in the response to H1N1. The experience with this pandemic illustrated that relying only on top-down planning by experts and specialists will likely (1) overlook important factors and complexities; (2) fail to adapt to the unexpected; and (3) result in lack of engagement and even mistrust among important stakeholders. This is also exuberated in the currently ongoing 2015 H1N1 outbreak in India (Annex 4).

5.2 Pre-Crisis

The pre-crisis phase is where an immediate threat has been identified, and is likely to affect a particular society. While there are no limits to the nature of such threats, the outbreak of the Ebola virus in West Africa in 2014 is a particular testimony to seriousness at this stage.

In the case of Ghana, the authorities had witnessed the outbreak spread throughout its neighboring countries with fatal consequences. Realizing the immediate threat, the Ghanaian government was swift to come up with a 'National Preparedness for Response Plan on Ebola'.

An important element in the plan has been the undertaking of a national stakeholders' forum, in which the private sector and civil society could provide input to the plan. Ghana being a complex state, with a modern and traditional state existing side-by-side, a particularly important virtue of the forum was to have Queen Mothers and chiefs as well as faith-based organizations weighing in on how they can contribute to the strategy³⁷.

5.3 Crisis

Subsequently the next case demarcates the transition from pre-crisis to crisis with the same case, though in another country.

Guinea in West Africa has been among the most affected countries by the Ebola virus disease. In rural Guinea, UNDP supported local authorities in risk communication. A particular initiative worth highlighting is collaboration with local religious leaders in explaining the danger associated with traditional burial practices and the Ebola virus.

As one of the predominant sources of Ebola infection is contact with corpses, the religious leaders (both Islamic and Christian) offered advice on handling of deceased using sealed sheets. This was a much-needed help, as there were reports of burial teams being chased out of the villages after telling locals that they must not bury their kinfolk according to tradition.

³⁷ <http://graphic.com.gh/news/general-news/33287-forum-on-ebola-held-in-accra-to-solicit.html>



UNDP stresses the importance of the contribution by stating that: “Such reinforcement from trusted leaders is vital. In an area badly shaken by the crisis, public support for the Ebola response is a vital step in preventing the spread of the disease³⁸.” Another aspect of the Ebola response in Guinea illustrates the value of participatory (rather than just top-down) communication, and also the value of international participation at the local level.³⁹

In 2012 the WHO created an Emergency Communications Network, a multi-national group of emergency communications experts who receive special training and can be deployed in humanitarian crisis and public health emergencies. Members of this group arrived in Guinea on March 31, 2014, six days after Guinea’s Ministry of Health formally reported an outbreak to WHO. The group included Dr. Pierre Rollin, an English- and French- speaking virologist, and Craig Manning, a health communications specialist.

In early April 2014, Rollin gave an update on Ebola at a press conference at the US Embassy in Guinea. At this point, there had been over 100 cases of Ebola in Guinea, with a 64% death rate, and the public was understandably nervous and wanting information. While Rollin was questioned by the media, Manning recorded Rollin’s clear explanations, and edited them into 10 broadcast-ready, 30-second segments, which were then distributed to local radio stations. Rollin and his colleagues were also extensively interviewed on local television as well as radio. While anecdotal, it was noted that when bystanders in the Guinea capital of Conakry were asked about Ebola during a mid-April CNN interview, they were able to accurately describe who was at risk.

It has been noted that during the Ebola outbreak in Africa, this sort of participatory, local, authoritative, interactive communication is more effective than remotely-produced “public service announcements”, which may provide good information, but make it easy for the listener to think “not in my back yard”⁴⁰.

5.4 Post-crisis

The European Union’s post-crisis response to H1N1 is a good example of attempting to learn from the experience of all stakeholders. In the aftermath of the H1N1 response, a multitude of assessments of the EU response were made by groups examining the various dimensions of the situation⁴¹. As a result of these assessments, a number of projects have been undertaken to improve EU’s preparedness, including ASSET, the project producing this report.

Having given warrant to the need of coining the concept “Crisis Participatory Governance,” this section has documented a series of empirical experiences and models for doing exactly that.

³⁸ <http://www.africa.undp.org/content/rba/en/home/presscenter/articles/2014/11/25/ebola-undp-reaching-out-to-guineans-one-household-at-a-time/>

³⁹ Centers for Disease Control and Prevention (2014)

⁴⁰ Ravelo (2014)

⁴¹ E.g., Health Protection Agency (2010), HEG Expert Group (2011)



co-funded by the EU. GA: 612236



share and move to face nasty bugs

While the examples here have been sporadic, we hope to contribute to the diffusion of Crisis Participatory Governance practices systematically to crisis situation and risk communication. However, the relationship between science and society is not without its challenges.



6. KEY ISSUES IN CRISIS PARTICIPATORY GOVERNANCE RELEVANT FOR PANDEMICS

Science and society are in all aspects mutually dependent upon each other. However, the relationship has always been fraught with difficulty. Whether it was Galileo's conflict with the Roman Catholic Church or the Stanford Prison Experiment, controversy is an integral part.

We now highlight and discuss key issues for crisis participatory governance relevant for pandemics. While such a discussion mainly consists of interrelated issues, we have for the sake of readability chosen to divide the discussion into three, slightly distinct, headings: Preparedness; definition; and trust.

6.1 Preparedness

A resilient society is prepared to handle exogenous shocks, as pandemics or natural disasters. This is typically manifested by a preparedness plan. However, the outbreak of H1N1 (the Swine Flu) directed attention to such plans often was informed by the SARS outbreak in the first decade of the new millennium. The Swine Flu was declared a pandemic on the basis of its global spread, not its deadliness as in the case of SARS.

While questions were raised on the extent economic interests governed the response to the Swine Flu, it was evident that future resilient preparedness plans needed a higher degree of flexibility. As such, the plans needed to accommodate different scenarios for the spread and deadliness of the disease. In the aftermath of the Swine Flu it became clear that the plan was not well-adapted to such requirements.

6.2 Definition

This leads to a discussion on the very definition of a pandemic. As such, public perception is linked to such devastating outbreak as the Great Influenza of 1918. However, improvements in hygiene and antivirals means milder, but more widespread diseases are now more likely.

This has led to the term 'pandemic' not holding a single uncontested meaning. Rather the term holds different meanings for different people along different dimensions:

- What is the geographical extension of the virus transmission (generically wide, or specifically in two, or more, WHO regions)?
- Does the emergency involve a new recombinant flu virus, capable of sustained transmission in humans whose immune systems haven't met it before?
- What is the health and socioeconomic burden of the disease, based on the number of cases, etc.?
- What is the severity/lethality of the disease⁴²?

⁴² Copied from the ASSET Communication strategy



One severe consequence of this is the effect the resulting misunderstandings have had on the level of trust in the authorities.

6.3 Trust in authorities

Under this heading two distinct situations will be dealt with. First the legacy of the Swine Flu, and second the formation of rumors in the case of Ebola in West Africa.

The major learning from the Swine Flu was that even the most resilient countries were not adept in the flexibility demanded in responding to variability of pandemics. Further, this led to questioning the applicability of the concept of a pandemic.

Consequently, at the moment, many people in Europe and USA credit WHO with crying wolf in 2009, driven by the pharmaceutical industry; and that flu is an insignificant disease and that pandemic flu is not a serious threat, nor a crisis.

The loss of confidence in international and national health authorities had a strong impact on vaccination too. Going beyond flu to other infectious diseases: from 2009 rumors and false myths about risks of vaccines changed the attitudes of many families, contributing to reduced immunization rates in some areas, leaving clusters of children unprotected, i.e. against polio, and preventing the achievement of important goals, such as measles eradication from Europe.⁴³

A second concern for the declining trust in institutional actors and other authorities is the genesis of rumors. Rumors are parallel information systems linked to the failure of genuine two-way communication systems.

In the case of the current Ebola epidemic many rumors have flourished. Amongst the most 'popular' is that Western health workers spread the disease, based on American imperialistic visions. This problem has manifested itself as locals hiding sick or dead people.

In summary,

- Different diseases imply different challenges, which in turn call for flexibility in the preparedness plans
- The terminology applied should be able to reflect the difference in lethality and spread
- Lack of trust in authorities may lead to rumors, hindering vaccination programs and other health care initiatives.

⁴³ Quotation from Copied from the ASSET Communication strategy



7. CONCLUSIONS AND RECOMMENDATIONS FOR THE TASK T2.7 TRANSDISCIPLINARY WORKSHOP

This report started with the concept of governance, which has been central to much political thought and action in the last decades. Governance exceeds or extends the concept of government both in scope and scale. Governance implies enforcement of decisions. Participatory governance means inclusiveness of citizens in decision making that has implications for their wellbeing and transparency in the decision making and implementation processes.

In this report, we have coined the term *Crisis Participatory Governance* to include citizens and civil society in risk communication and organized response to a crisis (i.e., epidemic and pandemics threats) so as to pioneer citizen engagement in policy making and implementation.

To fully utilize the potential of the Crisis Participatory Governance concept we have dissected it into four overlapping phases of Resilience and Sustainability, Pre-Crisis, Crisis, and Post-Crisis. We have dealt with different crisis participatory governance challenges associated with each phase. For each phase we have identified Crisis Participatory Governance Tools depicted in Table 2 above. We have also described some models and experiences of recent epidemics and pandemics in each of the four phases of Crisis Participatory Governance.

We have made number of suggestions for responsible research and innovations as explained in Section 3.6 Recommendations to Promote Participatory Governance. One of the research question is how to empower marginalized groups in society (i.e., women, ultra-poor, illiterate, physically and psychologically challenged, with lower social capital, and some ethnic groups) in participatory governance, and why they would participate when they have higher priorities, for example of hand-to-mouth existence. Another research area is how to improve willingness and capacity of state actor in participatory governance since it is a matter of culture, tradition, religion, legacy, and existing practices.

The task T2.7 Transdisciplinary Workshop, February 24-25, 2015, Geneva, aimed to consolidate tasks T2.1 to T2.6 outcomes, to cross-fertilize research, and to progress in the establishment of a transdisciplinary, common, approach among partners. Here T2.1 is Governance of Pandemics and Epidemics, T2.2 is Reference Guide of Unsolved Scientific Questions Related to Pandemics and Epidemics, T2.3 is this Crisis Participatory Governance report, T2.4 is Ethics, Law, and Fundamental Rights in Pandemics and Epidemics, T2.5 is Gender Issues in Pandemics and Epidemics, and T2.6 is Intentionally Caused Outbreaks.

For the T2.7 Transdisciplinary Workshop, the T2.3 team recommended three issues for consideration.

- First, how to make epidemic and pandemic resilient preparedness plans flexible enough to accommodate different scenarios for the spread and deadliness of the disease, and are tuned to local culture and traditional and religious beliefs?



- Second, how to disseminate to society the lethality and possible spread of the epidemic and pandemic, so that it does not cause panic and generate false belief?
- Third, how to create and sustain trust in society about vaccination and other public health initiatives, of the health professionals and policy makers, and curtail the spread of rumor mongering and myths related to epidemics and pandemics?



Annex 1

2011 South Sudan Secession Crisis Case Study

Sudan is faced with a tough situation after the secession of South Sudan in 2011. Internal and external pressures are increasing a conflicting context as the government tries to secure progress towards stable economic growth and peace. With oil revenues gone and instability in the region, there is an immense need for a process of recovery planning. Through coordination with UNDP's Crisis and Recovery Mapping and Analysis project, governments in Eastern Sudan, Blue Nile, South Kordofan, and Darfur have been able to create an evidence-base using participatory methodologies and novel technologies to relate with communities in recovery planning. Building on this work, UNDP's Conflict Reduction Program has supported State Peace building mechanisms in Blue Nile and South Kordofan in engaging communities to use the evidence-base, identify priorities for peace that would support recovery and reconciliation.

Participatory data collection methods help communities share their perceptions on a number of risks and threats to their livelihoods. These perceptions are then grouped and mapped to enable analysis and identification of interventions for recovery and peace building. The motivation for this work in Sudan has been to foster community engagement and state responsiveness for recovery programming in a post-conflict setting. Based on an initial plenary discussion, participants reach a consensus on the ten most critical risks and challenges facing their communities, which in turn provide the order of the day for the participatory mapping exercise. The mapping exercise sees participant's record perceptions and experiences through lengthy discussions, both on maps and datasheets. Each input is assigned an indicator and a specific geographic location in order to be incorporated in a GIS based database designed particularly for this purpose. Harnessing the power of crisis mapping and community engagement two of UNDP Sudan's flagship projects, have been exploring innovative methods for participatory recovery planning and response. In this way, Sudan, which is in an economic and social crisis, is trying to use participatory governance as a means of community engagement and relationship.



Annex 2

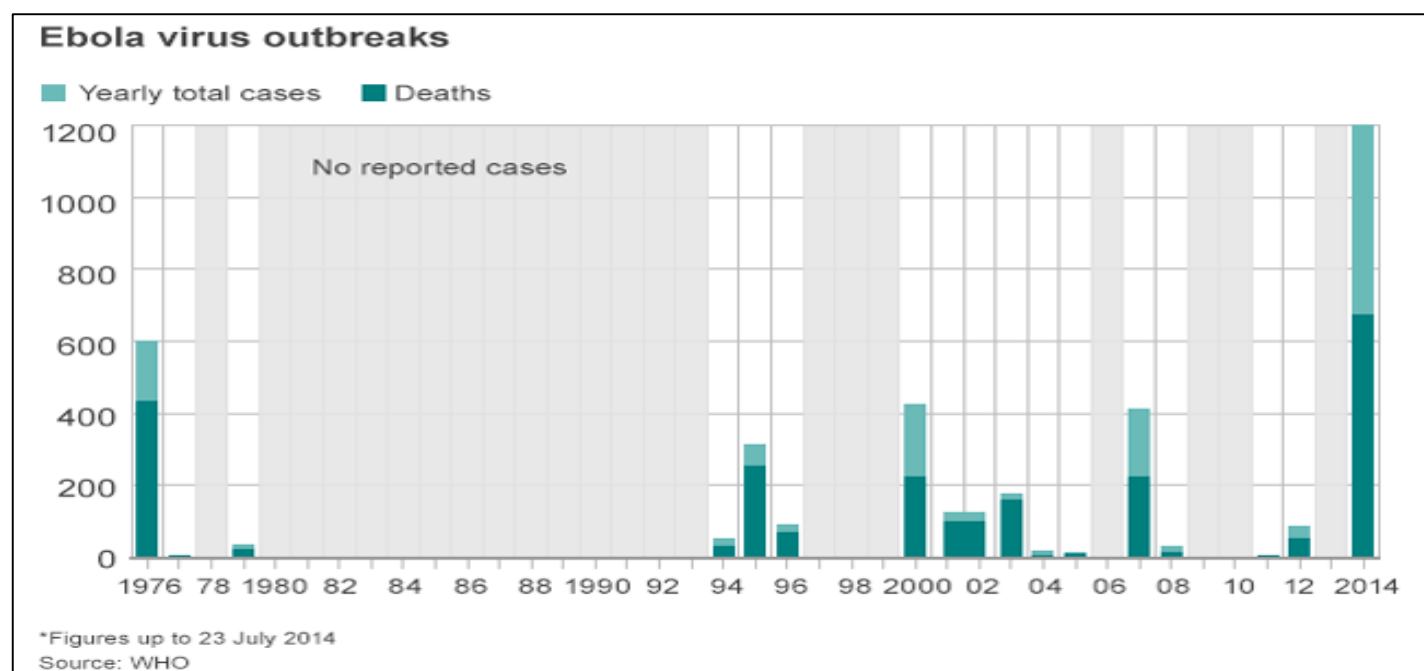
2014 Ebola Epidemic Case Study

Introduction

The Ebola crisis began in December 2013 in Guinea where the first case was reported. It was officially detected in March 2014 when the preventive action start to take shape. However with delay in control measures it had already spread to neighbouring countries like Liberia, Sierra Leone, Nigeria, and Senegal.

The Ebola virus is not airborne and thus chances of global outbreak were minimal as compared to SARS. It is transmitted through contact with bodily fluids.

It's not a new virus. It was previously detected in 1976 when it claimed 600 lives. This outbreak is bigger than that and it has claimed more lives. Fruit bats are hosts of Ebola virus. The virus can be transmitted directly from contact with fruit bats or through animals eating them. It cause severe acute viral illness with a fatality rate as high as 90%.



As of now there are only experimental vaccines for Ebola Vaccine. Though there have been many deaths, recovery has been possible with effective supportive.

Health care providers are particularly vulnerable as they are in touch with body fluids which can result in transmission of the virus. But they played a crucial role in making people of Guinea realize the nature of Ebola - its a dangerous viral fever and warranting an excess of precaution.



The outbreak has had huge repercussions on the economy of West Africa. Many flights to UK & US go via West Africa, and thus has hurt the other economies too. People stopped traveling to Africa and thus major travel revenues have been lost.

Countries with Widespread Ebola Transmission as of February 1, 2015

Country	Total Cases*	Laboratory-Confirmed Cases	Total Deaths
Guinea	2975	2608	1944
Liberia	8729	3143	3739
Sierra Leone	10740	8059*	3276
Total	22444	13810	8959

*Total case counts include probable, suspected, and confirmed cases.

Source: <http://www.cdc.gov/vhf/ebola/outbreaks/2014-west-africa/case-counts.html>

Models of Crisis Management

Government bodies in three crucial states - Guinea, Sierra Leone, and Liberia - established screening, quarantine and self-identification/ health protocols. UN established UN Mission's headquarter in Accra, Ghana to coordinate global efforts for controlling Ebola.

Models of Participatory Governance

MSF (Medicines Sans Frontier) has played a crucial role in setting up operation in the three countries and providing quick support. They have 300+ international professionals and 3,000 locally hired staff. They operate through seven Ebola case management centres.

US Centre for Disease Control (CDC) developed a special Ebola response team which reaches within hours of a confirmed case anywhere in US. Protocols related to isolation, recovery and contact tracing were established by state and local health authorities. Travel warnings have been issued by CDC for Guinea, Sierra Leone, and Liberia. They also monitor the health of suspected travellers for 21 days. Travellers are provided with information cards and thermometers, and they have to get daily medical check-ups with state and local health authorities.



Efforts were made by organisations from all nations, including Overseas Development Institute, Center for Disease Control and Prevention, the School of Oriental and African Studies, the International Medical Corps, and London School of Hygiene & Tropical Science. The experts identified certain key aspects to look for in participatory crisis management of Ebola.



City workers prepare to clean the streets in the centre of the Liberian capital, Monrovia. Photograph: Dominique Faget/AFP/Getty Images

They recommended community outreach to build trust and avoid any misconceptions. Rural communities have better outreach locally, and thus village chiefs and influencers were brought in to coordinate. People are also reached through radio, but reaching out personally and educating them about precautions has been more effective.

Contact tracing has been used through information card numbers so that crucial cases can be monitored. Proper procedures have been used when a person is found infected. He is carried in an ambulance with driver, nurse and two sprayers. The first sprayer sprays the house to disinfect it and carries the patient on a separate mattress. The other sprayer then sprays the first one, and incinerates all the medical equipment used. Frontline staff who dealt with patients were incentivised with proper hazard insurance so that they work freely.

There have been instances of outrage against medics used by Medicines Sans Frontiers and the International Federation of the Red Cross and Red Crescent Societies. People of villages would be resistant to them entering their villages, until false beliefs and rumors were countered by trusted sources within the villages.

There was also a shortage of resources, particularly at the beginning of the epidemic. Many health workers were deployed, but still lack of bed capacity and safety equipment resulted in an increased death toll. The international community has been establishing Ebola treatment centers, 17 such centres were established, many of which stand empty, having been completed too late to meet the timing of most of the victims.



Annex 3

2009 H1N1 Pandemic Case Study

Introduction to H1N1

H1N1 is a subtype of the influenza virus. It is known most widely for its outbreak in 1918 and more recently in 2009. Some strains of H1N1 are endemic to humans and possibly that is why the pandemic was so widespread. Mostly however, H1N1 strains are more common and endemic in pigs and birds. Hence it was nick named “Swine” flu during the 2009 crisis.

H1N1 is a respiratory illness that causes symptoms similar to influenza such as chills, fever, sore throat, muscle pains, severe headaches, coughing, weakness & general discomfort. To prevent spreading, the recommended time of isolation of an ill person is 5 days.

Transmission from pigs doesn't usually cause illness in humans, unless there is sustained and regular exposure to infected pigs. The pandemic originally started with H1N1 spreading among pigs and clinical signs appearing within 4 days of a pig getting infected. Transmission is generally known to be not caused by consumption of meat but through transmission of respiratory droplets. So is the case with human to human transmissions.

Introduction to the H1N1 Pandemic

According to the WHO reports as of July 2010, more than 18,000 people died in the pandemic directly by the virus. The total deaths including indirect causes is higher. Those without access to medical facilities went largely uncounted and were mainly based in Asia and South Africa. Experts including the WHO claim that the total death toll can be 284,500 with other research estimating it even upwards to about 579,000.

It first started in in the state of Veracruz, Mexico and it was already an ongoing epidemic for months before it finally broke out, in spite of the Mexican government trying to ward it off by shutting off various public and private health facilities.



In April, WHO deemed the situation as a “public health emergency of international concern” for the first time for any out-break. Subsequently in June, it was formally announced as a Pandemic. The number of cases steeply declined in November, 2009. However, only in August, 2010, the official announcement was made by WHO that the situation has moved in the “post-Pandemic” phase.

Travel precautions

These were very important and crucial to mitigate the further spreading of the virus and help contain it geographically.

Flu inspection on a flight arriving in China.



Travel agencies, globally complied and cooperated with the government and WHO guidance to filter out the infected. Examples are shown in pictures below.



Thermal imaging camera and screen, photographed in an airport terminal in Greece. Thermal imaging can detect elevated body temperature, one of the signs of swine flu.

WHO officially stated that banning travel and thereby trying to restrict the illness had implications on unrelated countries, economies and to some extent the relief efforts and thereby is not feasible. Thus, the focus shifted to scanning all passengers and infection vehicles at the time of entry and or exit. Further, those returning from infected areas would be tracked and if they exhibited symptoms, they would be quarantined. China, especially took the lead in this initiative. Additionally, they purified air and provided filtered air during flights and even masks etc. They even took additional initiative such as stepping up cabin cleaning, installing state-of-the-art air filters and allowing in-flight staff to wear face masks. Some studies reveal that filtering at travel points such as airports didn't really have much of a mitigatory effect but it is unquestionable that many of their processes and initiatives helped bring the pandemic to a stop.

Schools

The 2009 H1N1 Pandemic disproportionately affected the young and school-age people, between six months and 24 years of age. The H1N1 outbreak led to numerous precautionary school closures in some areas. Rather than closing schools, the US - CDC recommended that students and school workers with flu symptoms should stay home for either seven days total, or until 24 hours after symptoms subsided, whichever was longer. The CDC also recommended that colleges should consider suspending fall 2009 classes if the virus began to cause severe illness in a significantly larger share of students than the previous



spring. They also led schools to take initiatives such as suspending rules, such as penalties for late papers or missed classes or requirements for a doctor's note, to enforce "self-isolation" and prevent students from venturing out while ill. Schools also set aside rooms for people developing flu-like symptoms while they waited to go home and to have ill students or staff and those caring for them use face masks. Free masks dissemination, free checkup drives, education drives, meals at low costs, clean water and other such services were initiated by various schools and colleges.

When the worst case had been realized in a particular geography or populace, schools had been closed for extended periods. Even "influenza action teams" were formed in localities and schools were a crucial part of the organizing and executive teams.

Workplace

According to the U.S. Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention and the Department of Homeland Security (DHS) developed updated guidance and a video for employers to use as they developed plans to respond to the H1N1 outbreak.

These guidance suggested that employers consider and communicate their objectives, such as reducing transmission among staff, protecting people who are at increased risk of influenza-related complications from becoming infected, maintaining business operations, and minimizing adverse effects on other entities in their supply chains. Companies across wide geographies came together to implement these changes at a priority. Those that were slow, paid the price through infected workforce, public fines and loss of goodwill.

The CDC estimated that as much as 40% of the workforce might be unable to work at the peak of the pandemic. The CDC further advised that persons in the workplace should stay home sick for seven days after getting the flu, or 24 hours after symptoms end, whichever is longer. Similarly, In the UK, the Health and Safety Executive (HSE) also issued general guidance for employers.

Various organizations of all sizes participated and aided in the relief efforts to percolate into the last leg. Employees made organizations and joined hands to raise awareness, crowd source funding etc. Companies donated amounts of varying amounts towards relief activities.

Pigs and food safety

Although efforts were made to spread awareness that eating properly cooked pork or other food products derived from pigs will not cause flu. Nevertheless, in April, Azerbaijan imposed a ban on the importation of animal husbandry products from the Americas. The Indonesian government also halted the importation of pigs and initiated the examination of 9 million pigs in Indonesia. The Egyptian government ordered the slaughter of all pigs in Egypt in April 2009.

This had huge implications of farmers, breeders and various companies in the supply chain of meat (especially pork) and allied products. They were forced to comply and incur massive losses. Some others tried to revolt/ resist by raising awareness of the actual issues. The efforts however must be appreciated (in spite of limited efforts through widespread fear and hysteria).

Companies:

Companies cooperated on various fronts and put the pandemic on Priority. Pharmaceutical companies in particular were under a lot of pressure to manufacture H1N1 related drugs on priority and additionally to subsidize the same. Transportation and healthcare companies came together to deliver quick and cost efficient relief. Manufacturing companies such as 3M (dominant maker of respiratory masks) engaged



in a massive effort world-wide to help disseminate the masks in partnership with government agencies, healthcare providers, NGOs, etc.

Regulatory bodies:

Government agencies such as the CDC and the WHO played a vital if not the most important role in the global response efforts against the pandemic. They made & disseminated the overall strategy so all efforts everywhere were coordinated towards in goal complementing each other's efforts. Some do critique the methods employed by such organizations such as the WHO for example. It was argued that WHO's reactions to the situation didn't induce intelligent response but its rapid escalation of the pandemic communication, lead to massive hysteria and panic. In spite of this, such bodies were vital, else half the efforts of various stalk holders wouldn't have existed and the remaining half would not have happened. For example, such bodies, sponsored, studies around various themes around the situation and engaged the academia, elite business agents and consultants to coordinate the global efforts.

Conclusion:

The H1N1 Pandemic of 2009 was one of the major outbreaks in history and a disaster in its own right. Pressure of low healthcare facilities, hygiene habits, poor sanitation, public safety, public health & awareness had built up worldwide, especially in countries such as Mexico, South Africa and even in Asia.

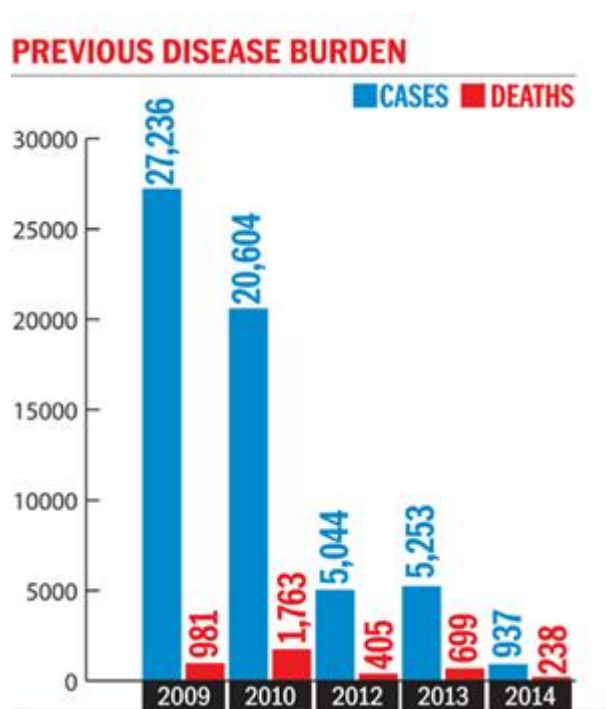


Annex 4

2015 H1N1 Outbreak in India

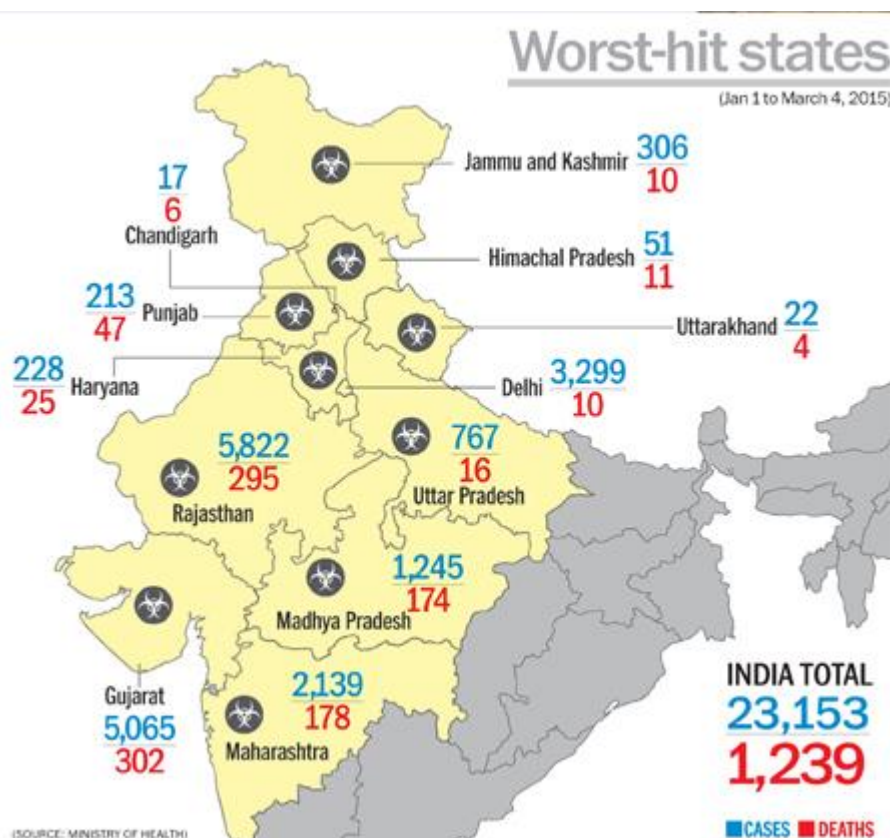
In India currently there is an outbreak of H1N1. **According to the Statesman / Asia News Network** quoting Indian Union Health Ministry sources, **1,401 persons had fallen prey to swine flu with the number of affected persons at 25,681 in 2015 till March 8** (<http://yourhealth.asiaone.com/content/swine-flu-death-toll-crosses-1400-mark-india>). In Rajasthan state 343 people died and 6,030 infected till March 9 (<http://www.rajswasthya.nic.in/CSSF.pdf.pdf>). In Gujarat state 342 people died and 5,623 infected till March 8.

The number of deaths in 67 days this year is nearly 6.5 times the whole of 2014 or more than any year since 2011. Even the number of affected people are nearly five times of the whole years since 2011.



A National Crisis Management Committee Meeting was held on February 19 chaired by Cabinet Secretary Ajit Seth to review the situation. The federal government has offered all the help to the states and asked the states to ensure round-the-clock functioning of outbreak monitoring cells.

After the death and infection of students, The Jamia Millia Islamia University, Delhi and Jodhpur National University have suspended classes till about February end. The Sardar Vallabhbhai Patel National Police Academy, Hyderabad closed for two days after eight Indian Police Service trainees and a child were tested positive for H1N1 virus. In Rajasthan state assemblies, including annual functions, in schools have been banned for about a fortnight till end of this month. The deaths and infected cases have occurred across India as can be seen from below:



The Australian Government has issued travel advisory, "If you are travelling to India, discuss influenza vaccination requirements with your GP or a travel health professional before departing Australia." The Associated Chamber of Commerce and Industry has estimated that the outbreak of H1N1 in Rajasthan and Maharashtra is expected to result in a loss of Rs. 5,500 crore (\$880 million) to the tourism and aviation industries.

Seventy percent of the deaths are occurring within two days of positively testing for H1N1. The main cause of fatalities is the late detection of disease since testing facilities are not available in rural areas (two out of three people live in rural areas in India) and late treatment.

Within the state of Rajasthan, maximum number of deaths have occurred in Jaipur district, 61. In the biggest hospital of the state, Sawai Man Singh Hospital in Jaipur the number of out-patients have become half of normal days due to the scare of the people for getting infected.

The positively infected people include incumbent Rajasthan Home Minister, former Chief Minister, a legislator, and health professionals also. The hospitals in Rajasthan do not have sufficient testing facilities and samples are being sent to out stations, which delays getting reports and treatment. About 1 million tamiflu tablets have been procured by the government for treatment. The state government claims that between 1 Jan. To 19 Feb. door-to-door survey for finding infected people was done by health teams in 2,476,728 houses. A local newspaper, Rajasthan Patrika, asked 100 homes if any health team has visited them. None of the surveyed people reported any health team coming to them, according to Feb. 20 edition of this paper. Advertising campaign are taking place. Some people are using face masks.

The Rajasthan state government has set up a Ashok Pangaria that daily reviews the position.

44 State Level Task Force for H1N1 headed by Dr. However, the Task Force consists of only



co-funded by the EU. GA: 612236



share and move to face nasty bugs

physicians and administrators and does not seem to have social scientists or other sectors of the society. Up-stream risk communication is also missing. It appears that the learning from the 2009 H1N1 pandemic has not percolated and is not practiced.



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