Data sharing in public health emergencies: Analysis of barriers and enablers from an outbreak response perspective (SHARE)

The case of Middle East Respiratory Syndrome (MERS)

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Case study report

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Executive summary

Timely access to data during infectious disease outbreaks by those involved in research preparedness and response provides essential input for public health response and for outbreak-related research. This may be clinical, epidemiological and laboratory data, including pathogen genomic sequence data. An additional aspect is the sharing and (international) shipping of samples in situations where local capacities for research are lacking or require more time to develop than is desirable during outbreaks. A multitude of interrelated barriers delay or obstruct timely sharing of data, frustrating efficient public health responses and ultimately the potential use of such resources in innovations. These barriers, typically summarized under the term PEARL (Political, Ethical, Administrative, Regulatory and Logistical), are complex in nature and difficult to circumvent, especially during outbreaks when multiple countries and sectors are involved. This is often the case when dealing with (re-) emerging zoonotic disease outbreaks, since transmission routes are complex, cross-sectorial collaboration is essential, and economic and social issues are usually involved. Barriers and enablers for data sharing may vary depending on priorities and perspectives from stakeholders. While some countries or institutes may perceive data sharing as a way to help others in diagnosing and responding to a biological threat, others who are in lack of the specific capacity might and sometimes do consider it as a form of exploitation or even 'biopiracy'. Under a One Health approach, a wide variety of stakeholders, with competing interests, different priorities, and ownership issues are manifold and need to be understood, to promote accessible and timely sharing of data as a key component of outbreak preparedness for (re-)emerging disease outbreaks.

Therefore, historical analyses of data sharing practices during past epidemic outbreaks that involved a wide variety of stakeholders were commissioned by the Wellcome Trust and The Department for International Development (DFID) of the UK. Collectively, these aim to provide an overview of critical lessons learned from past experiences and to support the development of sustainable data sharing practices for future research and infectious disease outbreak preparedness. This case study focused on outbreaks of MERS Coronavirus (MERS-CoV), as a new emerging zoonotic pathogen without a licensed intervention, to provide an in-depth understanding of barriers and enablers to data sharing to such zoonotic emerging infectious disease (EID) outbreaks.

Background on the Middle East Respiratory Syndrome (MERS) epidemic: a public health emergency of international concern?

The MERS epidemic started in 2012, caused by a newly emerging coronavirus, MERS-CoV. To date, 2,266 confirmed cases from 27 countries and 804 MERS-CoV associated deaths have occurred, according to the WHO. Although the disease has a zoonotic origin, large health care facility related outbreaks (e.g. hospital outbreaks) occurred in Saudi Arabia, the United Arab Emirates and the Republic of Korea. Camels were identified as an (asymptomatic) reservoir for MERS-CoV and as a potential source of human infections. How this transmission occurs, however, is not fully understood. As shown by the occurrence of 45 new cases of MERS in the past six months, including 14 deaths, MERS-CoV constitutes a constant public health threat. This threat is especially prominent in the Arabian Peninsula, where new introductions of the virus into the human population continuously take place and could potentially lead to further spread.

To address this threat, the timely and effective sharing of clinical, epidemiological and laboratory data, including pathogen genomic sequences is considered essential. The **overall goal** of the current study therefore is to improve global preparedness to infectious diseases outbreaks of public health concern by providing an in-depth understanding of barriers and enablers to sharing of clinical, epidemiological and

laboratory data, including pathogen genomic sequences, during the MERS-CoV epidemic, and by studying how data shaped research and public health responses to this outbreak.

Scope

The current study focused on the sharing of clinical, epidemiological, and laboratory data as part of the clinical and laboratory research preparedness and response to infectious disease outbreaks. In terms of MERS-CoV outbreaks, this case study focused on **primary transmissions at the animal – human interface in Qatar**, while also reflecting on the perspective from stakeholders from the wider region of the Arabian Peninsula. Hospital acquired infections were outside the scope of this case study. This case study considered different levels of data sharing representing the flow of data between stakeholders at different levels:

i) National, where data is shared among stakeholders within Qatar and is used to monitor population health, target response, and resource allocation,
ii) Regional, where data is shared among countries in the same region, or a group of countries with a collaborating institute or organization,
iii) International, where data is shared among countries and organizations outside the region, including research centers, and
iv) Global, where data is shared among international agencies, and inter-agency levels, and is used to estimate the global burden of disease and to contain emerging global health threats.

Methodology

The methodology used is in line with previous research on the topic of data sharing (Ribeiro et al., 2018). A comprehensive desk study was performed using 144 sources of white and grey literature, meeting- and press reports. This was used to reconstruct a detailed timeline of the MERS-CoV epidemic and the outbreak response including the flow of data as described in literature. Key stakeholders relevant to the response were identified from this map and 70 stakeholders were invited to participate. In total, 42 stakeholders participated in data collection (response rate 60%) including governmental representatives, public health experts, epidemiologists, clinicians, veterinarians, virologists, and social scientists. These stakeholders originated from public health or animal health institutes, academic research institutes, or supranational organizations. Combined, these stakeholders provided expertise relevant for all levels of data sharing (global, international, regional and national). From these participants, 27 key stakeholders were interviewed face-to-face or by phone. The semi-structured interviews followed a standardized interview guide. Additionally, 15 key stakeholders participated in a stakeholder workshop, divided into three groups for expert group discussions. The group discussions were performed according to a standardized format (1.5 hours in duration). From these interviews and workshops, a team of researchers inductively derived barriers and enablers to data sharing via thematic analysis. A root-cause analysis was performed to identify causal relations between barriers. Preliminary results were discussed with members of the study team, revised and used as input for this summary report.

Barriers and enablers to data sharing

The current research identified a list of 8 distinct barriers that were highly interconnected. Additionally, 18 distinct but interrelated enablers were identified. These barriers and enables were grouped into four categories:

i) Inclusive collaborations for global health, reflecting on collaborations between stakeholders across sectors, across different levels of data sharing and in a One Health approach
ii) Legal framework and authorization process, reflecting on regulations, guidelines and policies in relation to data sharing as well as the authority of stakeholders to decide on data sharing
iii) Ownership rights and interests of stakeholders in the assignment of ownership rights over data, as well as governance over its use
iv) Practical aspects of data collection, production and release, related to technical capability and capacity to generate and share data

While some topics were indisputable enablers to data sharing, others were identified as enablers in some circumstances, but also potential barriers when used or interpreted differently; such enablers were designated as situational enablers. Notable is the interconnection of these barriers at the different levels of interaction that were mentioned, indicating that the delay of data flow at one level affects the flow of data at or to another level. For example, the delays in notification channels and case definitions for animals at the global level affected the quality and completeness of data shared from a national level to the international and the global level.

Lessons learned and recommendations

Six main lessons were drawn from the stakeholders' experiences, and enablers and barriers. First, the importance of building and maintaining trust between sharing parties, based on a respectful collaboration, whether or not formalized through agreements governing data sharing. Second, the importance of bilateral data sharing and reciprocity of data sharing for sharing parties. The reciprocity of data sharing should be reflected in, amongst others, the assignment of ownership rights over data, in fair recognition of contribution to publications coming out of the data, and in capacity building. Third, the importance of inclusive inter-sectoral and One Health collaboration, based on a pre-organized stakeholder engagement with pre-defined roles and responsibilities of the stakeholders involved. Fourth, the need for the creation of a One Health preparedness and response system that fits all zoonotic EIDs with appropriate supportive technical infrastructure as well as pre-defined access rights and responsibilities of stakeholders. Fifth, the importance of having trusted international collaborating partners as external advisor and reference centers. Such international support for outbreak response is not only essential for low-capacity countries but all countries, which do not always have the expertise and experience for dealing with unknown or unexpected EIDs. Finally, barriers are highly interconnected in a multi-layered system of sharing, and therefore complex to solve. Therefore, addressing these barriers requires solutions that take into account the complexity and multitude of root causes that cause these barriers as well as how these barriers are reflecting upon each other on global, international and national levels of data sharing.

These main lessons learned provided the basis for the recommendations, which were categorized in recommendations to i) improve capacity and training, ii) create pre-established infrastructure and systems for data sharing, and iii) capitalize and build forward on pre-established collaborations based on trust and fairness of sharing.

Conclusion

The swift and transparent sharing of (confidential) data is a crucial pillar of outbreak response. This in-depth study of barriers and enablers to data sharing during the emergence of MERS-CoV provided

important insights that can be used to strengthen preparedness to zoonotic diseases, including the "Disease X" scenario listed a key priority by the WHO.

Introduction

Timely access to data during infectious disease outbreaks by those involved in research preparedness and response provides essential input for public health response and for outbreak-related research. This may be clinical, epidemiological and laboratory data, including pathogen genomic sequence data. An additional aspect is the sharing and (international) shipping of samples in situations where local capacities for research are lacking or require more time to develop than is desirable during outbreaks. A multitude of interrelated barriers delay or obstruct timely sharing of data, frustrating efficient public health responses and ultimately the potential use of such resources in innovations. These barriers, typically summarized under the term PEARL (Political, Ethical, Administrative, Regulatory and Logistical), are complex in nature and difficult to circumvent, especially during outbreaks when multiple countries and sectors are involved. This is often the case when dealing with (re-) emerging zoonotic disease outbreaks, since transmission routes are complex, cross-sectorial collaboration is essential, and economic and social issues are usually involved. Barriers and enablers for data sharing may vary depending on priorities and perspectives from stakeholders. While some countries or institutes may perceive data sharing as a way to help others in diagnosing and responding to a biological threat, others who are in lack of the specific capacity might and sometimes do consider it as a form of exploitation or even 'biopiracy'. Under a One Health approach, a wide variety of stakeholders, with competing interests, different priorities, and ownership issues are manifold and need to be understood, to promote accessible and timely sharing of data as a key component of outbreak preparedness for (re-)emerging disease outbreaks.

Therefore, historical analyses of data sharing practices during past epidemic outbreaks that involved a wide variety of stakeholders were commissioned by the Wellcome Trust and The Department for International Development (DFID) of the UK. Collectively, these aim to provide an overview of critical lessons learned from past experiences and to support the development of sustainable data sharing practices for future research and infectious disease outbreak preparedness. This case study focused on outbreaks of MERS Coronavirus (MERS-CoV), as a new emerging zoonotic pathogen without a licensed intervention, to provide an in-depth understanding of barriers and enablers to data sharing to such zoonotic emerging infectious disease (EID) outbreaks.

Background on the MERS epidemic: a public health emergency of international concern?

The MERS epidemic started in 2012, caused by a newly emerging coronavirus, MERS-CoV.[1] To date, 2,266 confirmed cases from 27 countries and 804 MERS-CoV associated deaths have occurred.[2] Although the disease has a zoonotic origin, large outbreaks occurred in Saudi Arabia, the United Arab Emirates and the Republic of Korea, associated to health care facilities (e.g. hospital outbreaks). Camels were identified as an (asymptomatic) reservoir for MERS-CoV and as potential source of human infections.[3] However, how this transmission occurs is not fully understood. MERS-CoV constitutes a constant public health threat, especially in the Arabian Peninsula, where new introductions of the virus

[1] Zaki AM, van Boheemen S, Besteboer TM, Osterhaus ADME, Fouchier RAM. Isolation of a Novel Coronavirus from a man with pneumonia in Saudi Arabia. New England Journal of Medicine, 367(19), 1814-1820.

[2] WHO Update on MERS-CoV situation, 27 November 2018. https://www.who.int/emergencies/mers-cov/en/ Accessed 30 November 2018.

[3] Reusken CB, Haagmans BL, Muller MA, et al. Middle East respiratory syndrome coronavirus neutralizing serum antibodies in dromedary camels: a comparative serological study. Lancet Infect Dis 2013 Aug 8

into the human population continuously take place and could potentially lead to further spread. For example, in the past six months 45 cases of MERS have been reported, including 14 deaths.

The **overall goal** of the study is to improve global preparedness to respond to infectious diseases outbreaks of public health concern by providing an in-depth understanding of barriers and enablers to sharing of clinical, epidemiological and laboratory data, including pathogen genomic sequences, during the MERS-CoV epidemic, and by studying how data shaped research and public health responses to this outbreak.

Scope

The study focused on the sharing of clinical, epidemiological, and laboratory data as part of the clinical and laboratory research preparedness and response to infectious disease outbreaks. This scope encompasses outbreak research involving:

- Epidemiological investigation and surveillance: tracking of cases and contacts, outbreak investigation, including identification of sources and transmission modes;
- Clinical research: research involving a substantial amount of work related to the observation of, data collection from, or diagnostic or therapeutic intervention on multiple or individual patients;
- Laboratory research: research involving all activities concerning laboratory outbreak response and research, including the sharing of microbial genetic resources, i.e. strains and genetic sequence data from pathogens and related metadata, samples, assays, protocols, and experiences.

In terms of MERS-CoV outbreaks, this case study focused on **primary transmissions at the animal – human interface in Qatar**, while also reflecting on the perspective from stakeholders from the wider region of the Arabian Peninsula. Thereby hospital acquired infections were outside the scope of this case study. This case study considered different levels of data sharing representing the flow of data between stakeholders at different levels, based on previous research describing different levels of data sharing generating corresponding different benefits[4]:

i) National, where data is shared among stakeholders within Qatar and is used to monitor population health, target response, and resource allocation,
ii) Regional, where data is shared among countries in the same region, or a group of countries with a collaborating institute or organization,
iii) International, where data is shared among countries and organizations outside the region, including research centers, and
iv) Global, where data is shared among international agencies, and inter-agency levels, and is used to estimate the global burden of disease and to contain emerging global health threats.

[4] Van Panhuis W, Proma P, Emerson C, Grefenstette J, Wilder R, Herbst A, Heymann D, Burke D. A systematic review of barriers to data sharing in public health. BMC public health 2014, 14(1), 1144

Methodology

The methodology used is in line with previous research on the topic of data sharing [5]. A comprehensive desk study was performed using 144 sources of white and grey literature, meeting- and press reports (See Annex I). This was used to reconstruct a detailed timeline of the MERS-CoV epidemic and on the outbreak response including the flow of data as described in literature (See Annex III). Although the scope of this study is MERS CoV outbreaks at the animal—human interface in Qatar, a broader consideration of events related to outbreaks in an international context was considered for a complete overview and understanding of relevant events and their co-relations, from the diseases emergence (patient "zero") until our current time. This activity resulted in a provisional overview of the actual course of events/facts and stakeholders involved, which was additionally used to make an individualized summary of contributions in preparation of the interviews, still with gaps and uncertainties that were filled in and checked during the interviews. Key stakeholders relevant to the response were identified from this map and 70 stakeholders were invited to participate through various approaches including the personal networks, emails or phone calls as appropriate to their culture and context. The invitation included information about the study design, aims, expected time investment and other practical arrangements (e.g. confidentiality and informed consent).

The following inclusion criteria were applied:

- Work of stakeholder is/was related to MERS-CoV public health response or related research during the outbreaks
- Stakeholder has/had authority to make (a) decision(s) on data sharing or a key role in or key influence on data sharing within their level of data sharing (national, regional, international, global)
- Stakeholder is/was collaborating and sharing data with stakeholders from Qatar
- Stakeholder is/was involved in laboratory or public health research that directly or indirectly shaped the public health response in Qatar
- Stakeholder was involved in crucial phases of the timeline for public health response and outbreak related research

In addition, the following stakeholder exclusion criteria were applied:

- Stakeholder does not agree to participate
- Stakeholder is unavailable during time frame of data collection of this case study
- Stakeholder feels he/she has not much to say or has insufficient knowledge about the topic of the case study and/or refers to others for answering to case study interview questions
- Stakeholder is part of the case study team

In total, 42 stakeholders participated (*response rate* 60%) including governmental representatives, public health experts, epidemiologists, clinicians, veterinarians, virologists, and social scientists from: public health or animal health institutes, academic research institutes, or supranational organizations (See Figure 1). Combined, these stakeholders provided expertise relevant for all levels of data sharing (global, international, regional and national). However, the underrepresentation of stakeholders from the regional level of data sharing should be noted as a limitation, due to a lack of response and unavailability to participate within the timeframe of our case study. From the participants, 27 key

[5] Ribeiro C, van Roode M, Haringhuizen G, Koopmans M, Claassen E, van de Burgwal L. How ownership right over microorganisms affect infectious disease control and innovation: A root-cause analysis of barriers to data sharing as experienced by key stakeholders. PLoS One 2018; 13(5)

stakeholders were interviewed face-to-face or by phone. The semi-structured interviews lasted at minimum 36 minutes and at maximum 78 minutes, and followed a standardized interview guide (See Annex II). The questions were designed to address six overarching topics: the stakeholder's role and contribution on the MERS-CoV research and response; the stakeholder's knowledge and/or perceptions on the data sharing practices that took place; how these data was applied in the public health research and response; the stakeholder's knowledge and/or perceptions on enablers and barriers to data sharing; and finally possible lessons learned and recommendations for future outbreaks. The informed consent procedure included permission to record the interviews and to use the anonymized data in further publications. The interviews were recorded, transcribed, and coded to ensure anonymity of the stakeholders. Additionally, 15 key stakeholders participated in a stakeholder workshop, divided into three groups for expert groups discussions. The group discussions were performed according to a standardized format (1.5 hours in duration), and aimed to gather feedback from national stakeholders on the interim case study results. The stakeholders discussed the results in light of the (anonymized) overall viewpoints and experiences of other stakeholders, thereby aiming to converge towards a common understanding of enablers and barriers and decisions on actions to improve data sharing.

Invited	70	**Participated**	42
Response rate	60%		
Sector			
-	Supranational organization		8
-	Public health/ animal health institute		24
-	Academic research institute		10
Level			
-	Global		6
-	International		10
-	Regional		2
-	National		24
Domain			
-	Human health		32
-	Animal health		8
-	Food safety		2

Individual interviews		
Total		**27**
-	Global	7
-	International	9
-	Regional	2
-	National	9
Expert group discussions		
Total/National		**15**
-	Public Health	4
-	Animal Health	5
-	Academia	2
-	Laboratory	4

Figure 1 Stakeholders response rate was 60%. Stakeholders represented different sectors, levels of data sharing, and domains reflecting their main area of expertise (left table). Right table shows representation of stakeholders who were individually interviewed (top) or participated in the expert group discussions (bottom).

The data collected from the variety of data sources (literature review, workshop and interviews) were thematically analyzed. To this end, a code book was developed that allowed us to quickly retrieve and compare information across data sources on key aspects. The code book was developed iteratively, allowing for the emergence of new themes as the analysis progresses, but initially the code book was developed around key aspects of data sharing as described in literature (timeliness, quality, authorization, equity, etc.). For the data analysis, five predetermined steps were followed: familiarization, identifying the thematic framework, data indexing, data charting, data mapping, and data interpretation.[6] The reconstruction of interpretative frames technique was used to get acquainted with the stakeholders' perceptions and interests on data sharing during the MERS-CoV outbreak, and

[6] Ritchie J, Spencer L. Qualitative data analysis for applied policy research. The qualitative researcher's companion. 2002; 573, 303-329

enablers and barriers.[7] A root cause analysis was performed to identify causal relations between barriers (Ribeiro et al., 2018). Finally, all findings were brought together to appropriately contextualize them. A cross-cutting analysis devoted specifically to integration and interpretation of our observations was performed, and included a gap-overlap analysis to highlight where the findings reinforce and/or contradict each other. Based on a secondary analysis of the study data, reasons for any discrepancies were analyzed and synthesized. This enabled us to highlight critical lessons learned from past experiences and to support the development of recommendations for sustainable data sharing practices during future research and responses to (re-)emerging disease outbreaks. To this end, iterative discussions were held with the researchers who principally collected and analyzed the data, followed by discussion of the preliminary results in a video conference with members of the study team. Final results were revised and used as input for this summary report.

This case study has received ethical approval from Erasmus MC Medical Ethical Committee (approval reference number MEC-2018-1365).

[7] Grin J and van de Graaf H. Technology assessment as learning. Science, Technology and Human Values 1996, 20(1), 72-99

Data sharing practices during the MERS-CoV epidemic

Before a comprehensive description of barriers and enablers to data sharing that were experienced by the study participants was provided, data sharing practices were revealed that were used by the study participants to share data during the MERS-CoV epidemic to understand the definition of key data in the context of the epidemic according to the study participants and to what extent data sharing occurred during the epidemic.

Types of data

The types of data study participants mentioned to have shared that they felt were crucial for the outbreak/public health response or for outbreak related research are listed below. These types of data were categorized into three categories based on different considerations for data sharing in public health emergences in each of the categories, using the WHO policy statement on data sharing in the context of public health emergencies as guidance document.[8]

1. ***Data related to and/or necessary for outbreak surveillance, epidemiology and emergency public health response***
   - **Epidemiological investigation data - human**:
     - Confirmed case notifications
     - Suspected case notifications
     - List of confirmed human cases per country
     - Epidemiological evidence of human-to-human transmission (contact tracing)
     - Suspected and/or confirmed sources (exposures) related to human cases
     - Risk factors for acquiring infection
     - History of travel of cases
   - **Epidemiological investigation data - animal**:
     - Confirmed notifications of infection (sero-positivity)
   - **Laboratory/ clinical diagnostic data**:
     - Case definitions of infections, i.e. diagnostic analyses of samples
     - Diagnostics kits, assays and related materials (e.g. antibodies and reagents) for use
     - Serological data from surveys to assess the extent of the outbreak
   - **Information related to epidemiological investigation and surveillance as part of the public health response**:
     - WHO guidelines for surveillance, case definition and laboratory testing, case investigation, and infection control
     - Reports on IHR notifications
     - OIE guidelines for case definition
     - Clinical guidelines for treatment of cases
     - Scientific/ evidence based protocols for sampling and diagnosis
     - (National) outbreak response plan/ strategies used, and level of preparedness
     - WHO guidelines on the laboratory safety
     - Global risk assessment and trends, and interpretation of shared sequences

[8] WHO Policy Statement on Data Sharing by the World Health Organization in the Context of Public Health Emergencies, 13 April 201, available online via www.who.int

2. ***Genetic sequences and biological samples***
    - Pathogen genomic data (sequence data)
    - Pathogen genomic data (virus)
    - Samples from patients and/or suspected cases
    - Samples from animals (mainly camels)

3. ***Data related to/ necessary for outbreak related research***
    - **Clinical/ epidemiology research data - human**:
        - Patient statistics (related metadata): sex, age, disease history and comorbidities, demographics and place of residence at time of start symptoms (if not considered confidential data), date of sampling, type of sample
        - Clinical observational data: description of the case, status of the case, date of onset, date of hospitalization and lab testing, natural history of disease and clinical presentation (clinical course of infection, including disease symptoms and disease outcome)
    - **Epidemiology research data – animals**:
        - Epidemiological observational data and statistics: age, place and country of origin, location of sampling, date of sampling, type of sample, natural history of infection (if any), husbandry practices, animal movement (trade and market information)
    - **Laboratory research data**:
        - Novel diagnostics for both human and animal populations and related materials (e.g. reagents) for use
        - Culture systems for the virus
        - Guidelines on and cross-validation of diagnostics (already in use and in development)
        - Data on pathogen and transmission: source attribution (main animal reservoir and source of zoonotic transmission to humans), dynamics of transmission events (e.g. routes of exposure), geographic distribution, circulation of virus in human population (sero-prevalence), circulation of virus in animal population (sero-prevalence), virus isolation data, viral evolution and genotypic correlates of viral sequences
        - Data on pathogen-host interaction: viral tropism, receptor data
        - Relevant (small) animal model experiments

Data sharing mechanisms

The following commonly used mechanisms of data sharing were used by the study participants to share data during the MERS-CoV epidemic. These included formal and informal mechanisms for data sharing. The mechanisms were divided into open access sharing mechanisms and closed access sharing mechanisms.

- **Open access sharing mechanisms**:
    - Open access databases (GenBank)
    - International scientific meetings (*semi open access*)
    - Scientific publications and supplementary material in journals
    - Countries and institutional websites
    - Public/online notifications, guidelines and reports (ProMed, WHO and OIE meeting reports and online updates, e.g. Disease Outbreak News, DON)
    - Press conferences, press releases (media)

- **Closed access sharing mechanisms**:
    - Countries internal public health databases and surveillance systems
    - Closed consortia:
        - Research field investigation teams/ missions
        - European Commission funded consortia
    - Informal professional networks
    - WHO (technical) meetings
    - Confidential communication through calls, e-mails and face-to-face
        - WHO teleconferences
    - Notifications to WHO and OIE, through countries animal and public health authorities, including IHR focal points
    - Notifications to ECDC through IWRS system
    - IHR Event Information Site (EIS, closed database for Members States' IHR focal points)

Barriers and enablers to data sharing

This case study identified a list of barriers and enablers, grouped into four categories: i) inclusive collaborations for global health, reflecting on collaborations between stakeholders across sectors, across different levels of data sharing and in a One Health approach, ii) legal framework and authorization process, reflecting on regulations, guidelines and policies in relation to data sharing as well as the authority of stakeholders to make decisions on data sharing, iii) ownership rights and interests of stakeholders in the assignment of ownership rights over data and its use, as well as its governance, and iv) practical aspects of data collection, production and release, related to technical capability and capacity to generate and share data (Figure 2). Some of the observed categories were identified as enablers in some circumstances, but also potential barriers when used or interpreted differently, and designated as situational enablers. Each category is discussed in more detail in the sections below.

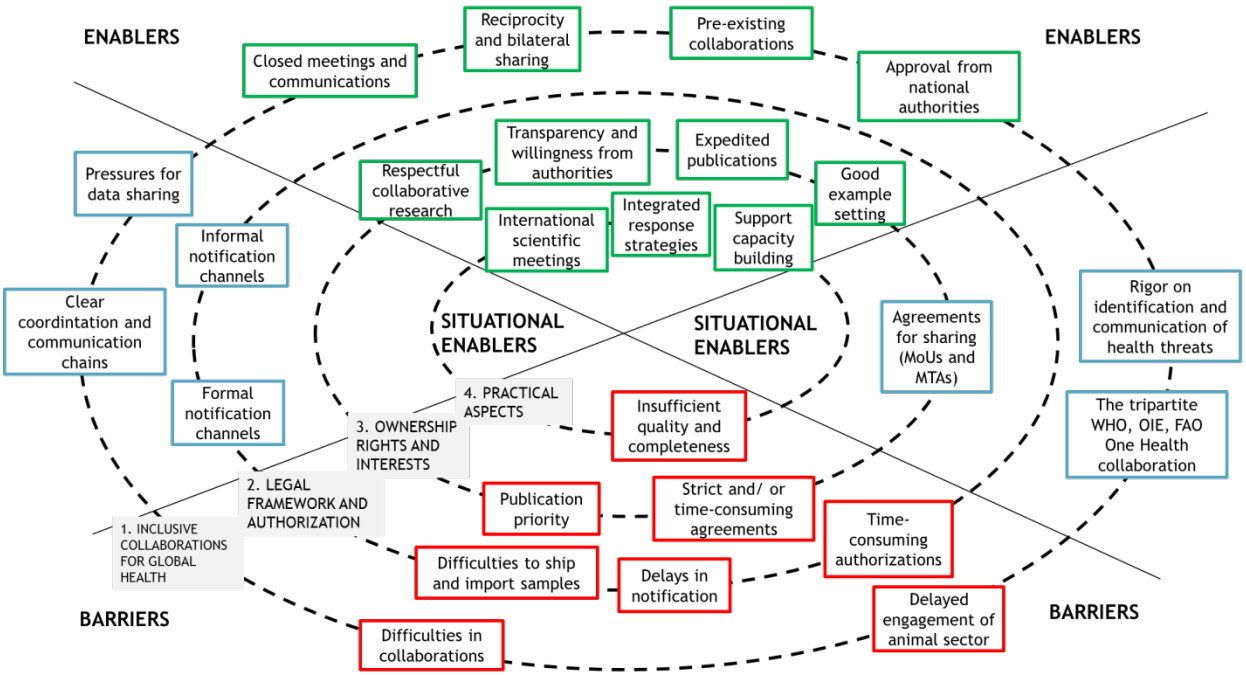

Figure 2. Overview of barriers and enablers of data sharing grouped into 4 main categories (indicated as dashed circles with numbered grey textboxes). Some enablers were context dependent to either facilitate or hamper data sharing, shown in blue as situational enablers. Red topics represent barriers and green topics represent indisputable enablers.

Barriers to data sharing

The study participants mentioned many barriers that either hampered or delayed data sharing during the MERS epidemic. The root cause analysis defined 8 distinct barriers that were highly interconnected as shown by the connection of causes and root causes for distinct barriers (Figures 3 - 6). The figures were drafted based on the arguments provided from the stakeholder interviews and workshops. For instance, some stakeholders mentioned that the deeply rooted cultural importance of camels (Figure 3, right column) led to debate on the credibility of camels as a reservoir (argument column, top), but also the need for confirmatory testing as camels were asymptomatic (argument column, second argument).

Inclusive collaborations for global health (outer circle no. 1, Figure 2)

Two barriers were related to inclusive collaborations for global health for their causal analysis. These are delayed engagement of the animal sector and the difficulties in multi-sectoral collaboration between public health, animal health and research institutes (academia) and One Health collaboration. Root causes related to cultural, social and economic importance of camels, different interests and priorities of stakeholders as well as the observation that pre-established collaborations between stakeholders were not of not sufficiently defined to deal with zoonotic EID outbreaks (Figure 3).

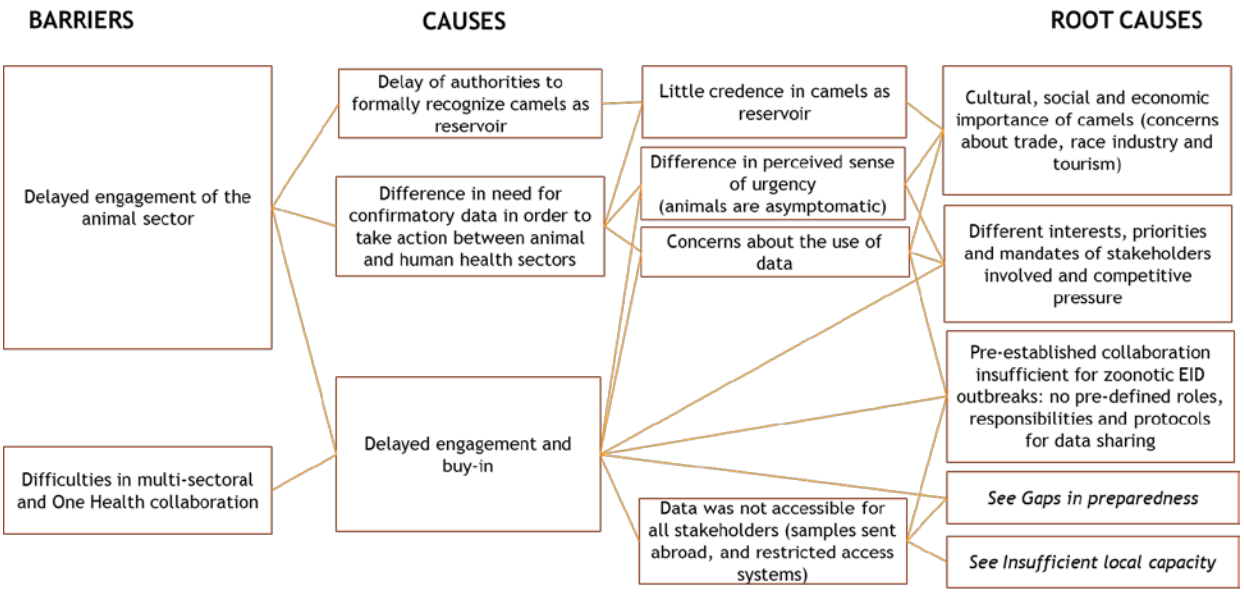

Figure 3 Causal analysis of the two barriers related to inclusive collaborations for global health. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

Legal framework and authorization process (circle no. 2, Figure 2)

This barrier category is composed of three distinct barriers reflecting delays in notification of MERS-CoV infections, time-consuming process to obtain authorization to share data, and difficulties to ship and import samples (see figure 4). Some of the causes and root causes originated from other barrier types, such as inclusive collaborations for global health and practical aspects of data collection, production and release.

Ownership rights and interests (circle no. 3, Figure 2)

The last category of barriers relates to ownership rights and interests and constitutes of two barriers, strict and/or time-consuming agreements that limit data sharing and the importance of priority in scientific publication (see figure 5). Most of the root causes underlying these two barriers related to the uncertainty and lack of control over the use of data once it is shared.

Practical aspects of data collection, production and release (Inner circle no. 4, Figure 2)

The barrier that related to practical aspects of data collection, production and release was the insufficient quality and completeness of data (Figure 6). Most root causes related to gaps in the preparedness for dealing with zoonotic EID outbreaks either at the human-animal interface, at a technical level (e.g. laboratory capacity) or at a cultural level.

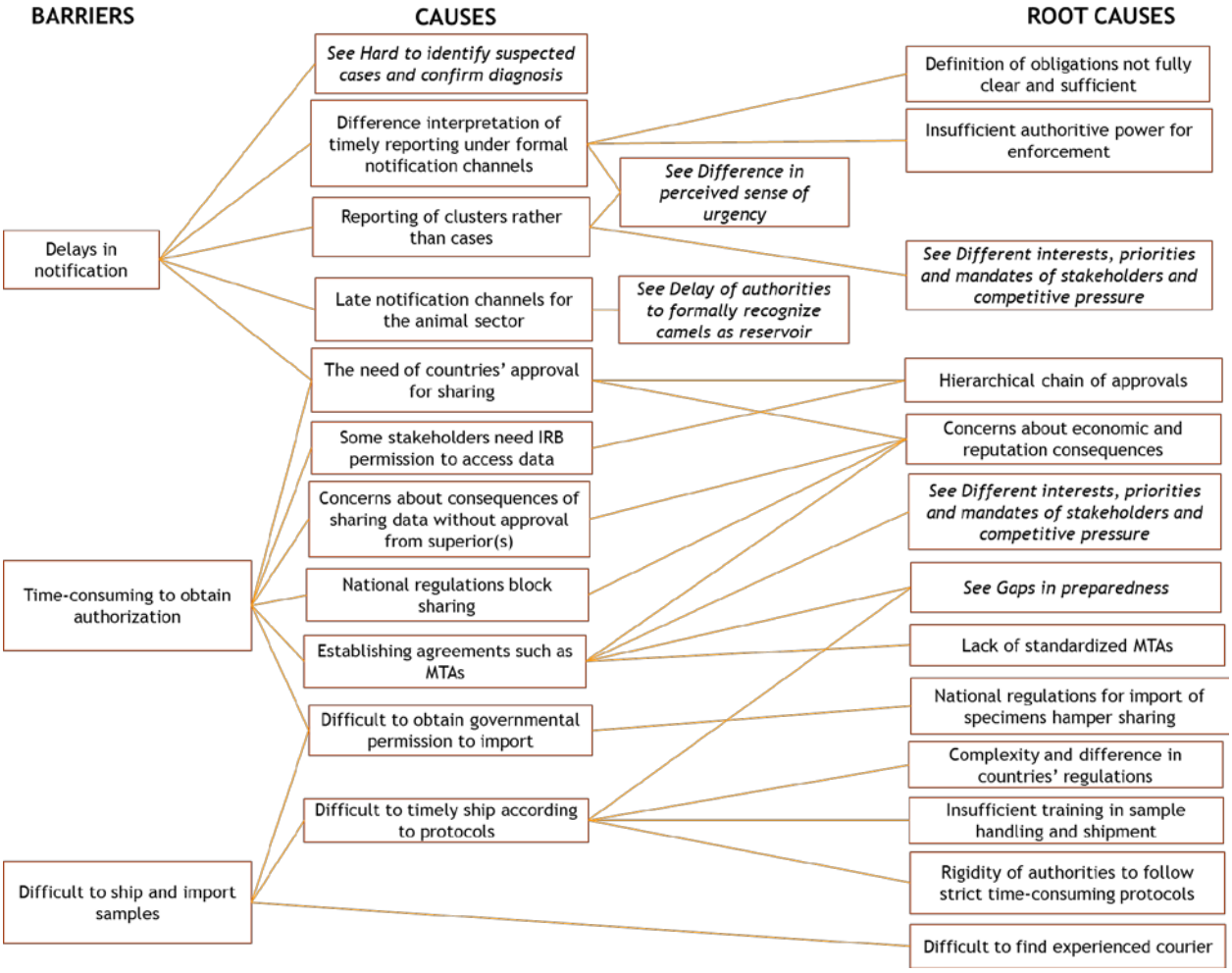

Figure 4 Causal analysis of the three barriers related to legal framework and authorization process. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

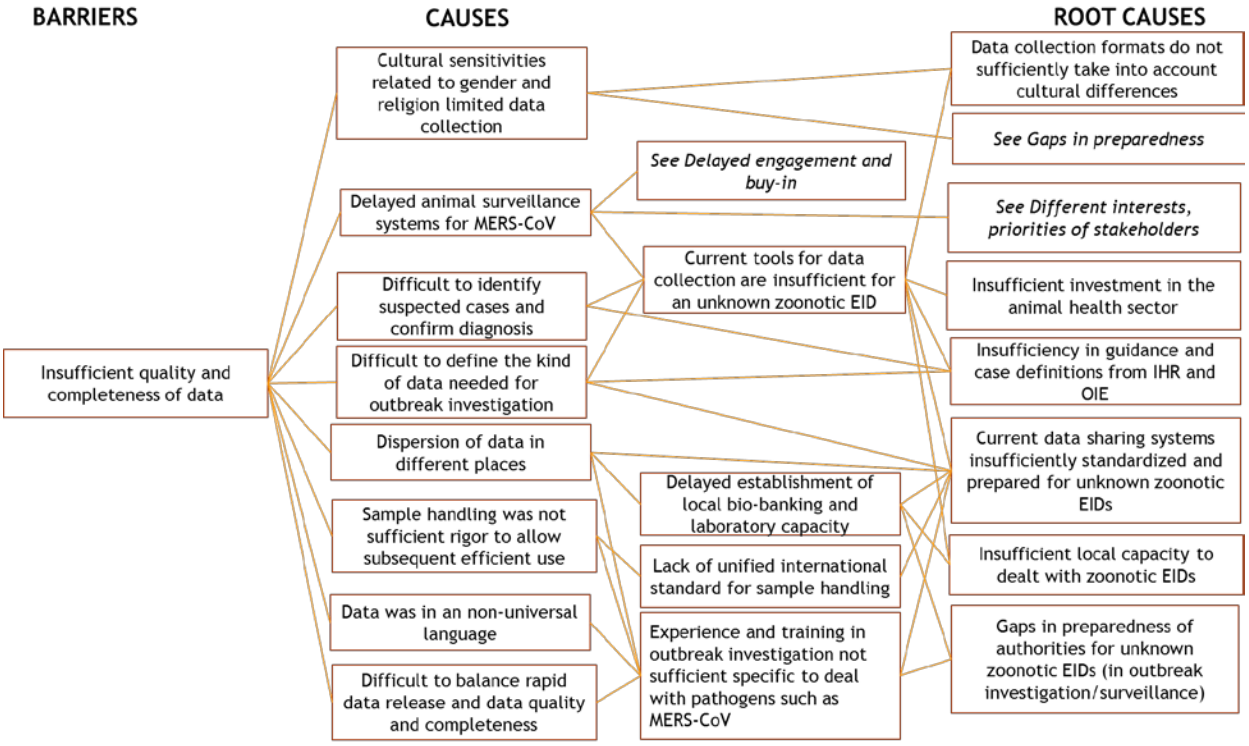

Figure 6 Causal analysis of barrier related to practical aspects of data collection, production and use. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

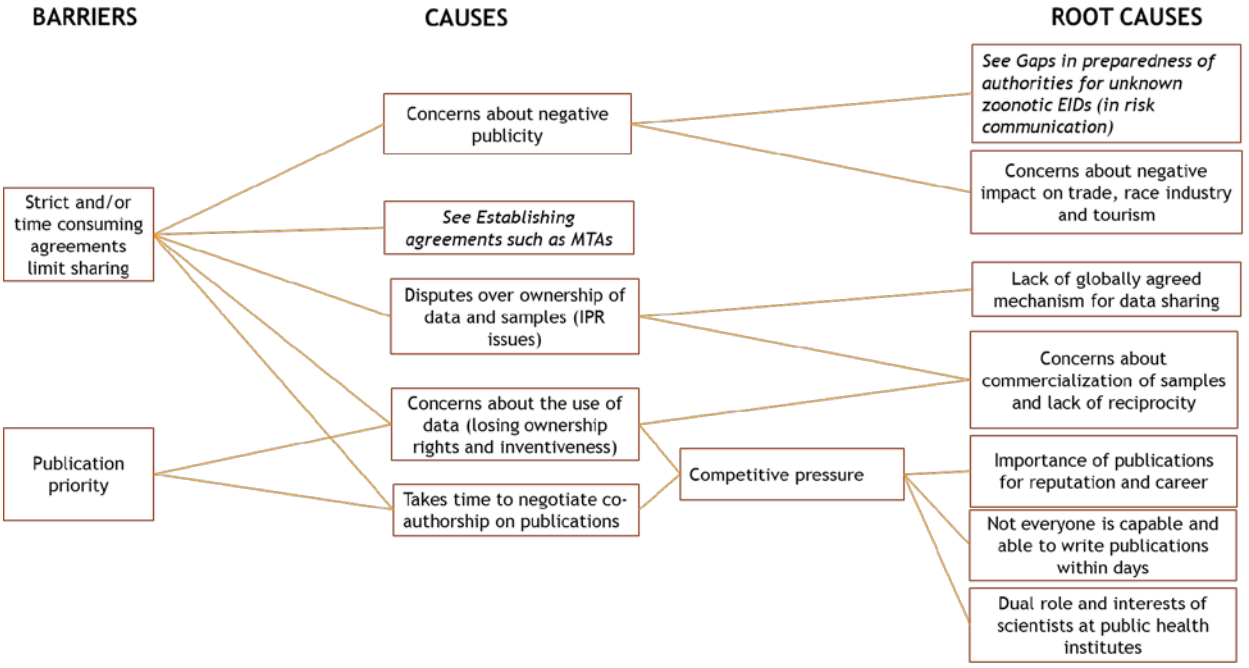

Figure 5 Causal analysis of the two barriers related to ownership rights and interests. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

Impact of barriers at the different levels of data sharing

In a multi-layered system of data sharing, where flows of data sharing exists on global, international and national level as well as between each of these levels, barriers that affect data sharing on one level also had an impact on the sharing of data in other levels, thereby ultimately impeding the public health response of stakeholders to the MERS epidemic (Figure 7). For example, the delays in establishing appropriate notification channels and case definitions for MERS-CoV infection in animals at the global level affected the engagement of the animal sector as well as the quality and completeness of data shared from a national level to the international and the global level. Some barriers affect data sharing within and between all levels of data sharing, such as insufficient quality and completeness of data, whereas some barriers appear to more specifically affect data sharing, e.g. difficulties to ship and import samples affected data sharing between national and international stakeholders as well as between international stakeholders.

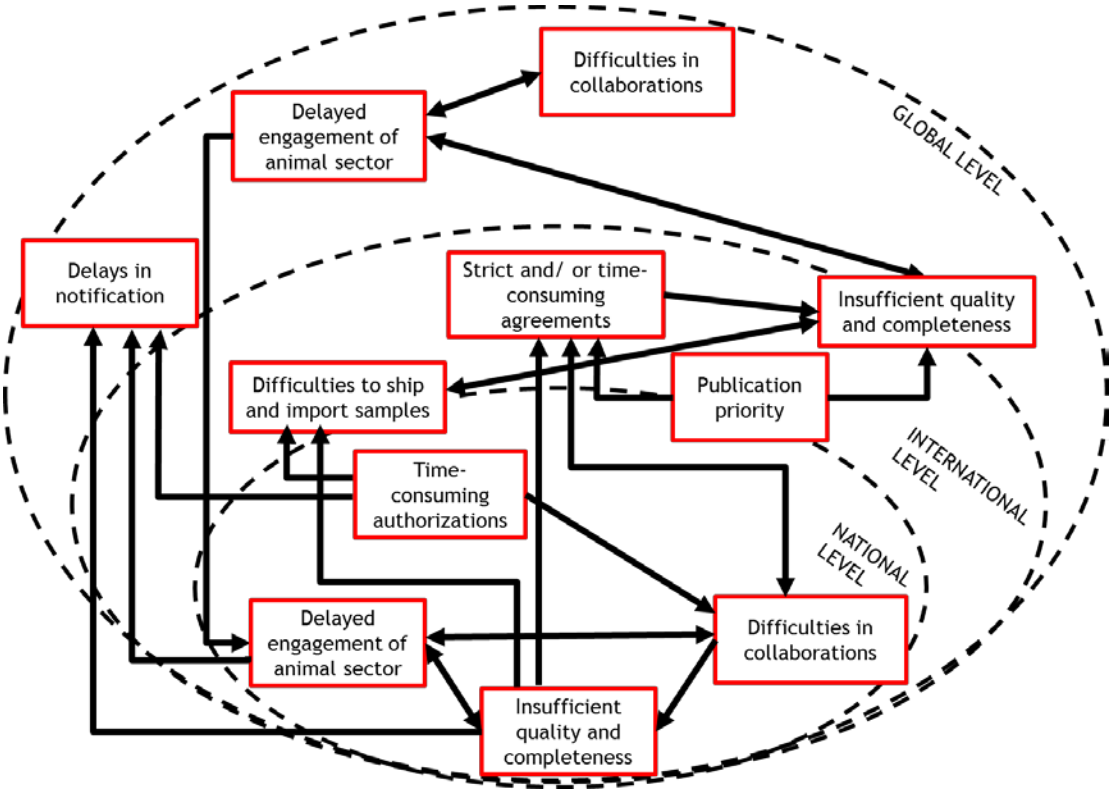

Figure 7 Regrouping of the different barriers to reflect at which level of interactions they were mentioned shows that barriers affecting data sharing on one level also had an impact on the sharing of data in other levels. Arrows show that barriers hampering data sharing at one level affect the flow of data at other levels. One-sided arrows indicate a unidirectional causal relation (cause-consequence), whereas two-sided arrows indicate a bilateral causal relation.

Enablers to data sharing

The study participants mentioned many enablers that either motivated or facilitated data sharing during the MERS epidemic. These enablers were organized into 18 distinct but interrelated enablers that were classified in the four different groups indicated in the dashed circles in Figure 2. A key finding for the identification of enablers to data sharing, was that while some topics were indisputable facilitators to

data sharing, others were context dependent having the capacity either to facilitate or hamper data sharing depending on the situational context in which they occurred or were implemented. The context-depended enablers are highlighted, in this session, in each of the groups of enablers as *situational enablers*. Figure 2 shows this spectrum of enablers and situational enablers in relation to barriers classified in each of the four groups.

Inclusive collaborations for global health (Outer circle no. 1, Figure 2)

Pre-existing collaborations and sharing systems

The pre-existence of collaborations and systems supporting data sharing were mentioned as an essential foundation that could be extended to further support data sharing during the MERS epidemic or other outbreaks. In relation to international collaborations, stakeholders mentioned two key factors that play a decisive role on their choice of who to collaborate with. The first factor is previous or pre-existing collaborations, because stakeholders already knew each other and had a trustworthy relationship. The second factor is the advice (and engagement during in-country missions) from supranational organizations, on which parties worldwide have the expertise and good reputation for collaborations, also based on the experience of the supranational organizations in previous collaborations with parties.

"*The decision of who to collaborate with is usually a decision done in conjunction with our labs and the public health department. The labs usually have several international collaborators, and the public health departments also already have their collaborators, or they rely on WHO to indicate some collaborators… WHO help to identify reference labs for us and they start the collaboration, and they recommend using a MTA to shipping samples abroad*."

In relation to pre-existing systems for sharing, the One Health networks that were in place for pandemic influenza and SARS were mentioned to be great facilitators for the implementation of One Health collaborations for MERS since, besides the other pre-existing collaborations, there was experience and even mechanisms in place for sharing data with each other.

"*We had this collaboration already in place for the animal and human sectors, especially for bird flu, and in MERS we build from this"*

Reciprocity and bilateral sharing

The feedback on the data shared, on the form of information, analysis and capacity building, were mentioned as important motivators for stakeholders to share the data. Examples of such feedback were the provision of protocols and guidelines from supranational organizations and support on research and response from international institutes, especially through the provision of diagnostic tests and training on how to use such tests. The reciprocity of data sharing and bilateral sharing was facilitated by the establishment of Memoranda of Understanding and Material Transfer Agreements.

"*And we did not have the tools to test and that was a dilemma for us, we do not know what we are dealing with. We had to send samples abroad for communicating to our public health department what we could do to have these tests, were the tests commercialized? Were them suitable for us? That was a period of uncertainty. But fortunately, things moved quickly and we started to have the tests from an international research institute, they came here they trained our colleagues. And we also had collaborations with another institute for the human and animal health lab*."

Approval from national authorities for data sharing

The endorsement of national authorities for (One Health) collaborations and data sharing helped the engagement and collaboration of the diverse national stakeholders. This is closely related to the transparency and willingness to share data from national authorities (further elaborated below under

ownership rights and interests), as well as integrated response systems with endorsement of national authorities.

"But regarding data sharing, if the seniors are committed, they are supportive on sharing and getting the appropriate control measures in place, it really helps a lot. And with good resources we can have good measures."

Closed face-to-face meetings, calls and mails

Meetings like the WHO's emergency committee and closed communications, including informal ones, which allowed direct and open conversations were mentioned as facilitators to data sharing, because in these close meetings stakeholders committed to confidentiality.

"*There were very difficult discussions during those closed calls and the reports, or internal notes, those are confidential meetings and there is a reason for that. …… countries were directly called out on not sharing info and on secrecy, working with specific academic groups and keeping it in a confidential manner….."*

Clear coordination and communication chains (***Situational enabler***)

At the national level it was mentioned that good coordination for data sharing with clear communication chains helped the sharing of data and increased the confidence of stakeholders when sharing. Nevertheless, when such channels are built upon strict hierarchical processes of approvals, limiting the flexibility and empowerment from the different stakeholders on the decision of collaborating and sharing data, this creates delays that are detrimental to timely sharing.

"*I am more comfortable to share the data with the animal health sector under the umbrella of the Ministry of Public Health. I do not want to breach any confidentiality or approval chain*."

"Not all the information can be shared unless you have an approval from sometimes the highest level and sometimes from our managers. Overall it is not a problem, only we need to have an approval, we cannot share it unless we have an approval"

Pressures for data sharing (*Situational enabler)*

Rumors coming from the media, as well as criticism from the international community, and strong-worded advice from supranational organizations were referred to as outside pressures motivating data sharing that led gradually to an improvement in transparency and sharing from affected countries. Still, at an early stage in the MERS epidemic, the criticism to Saudi Arabia for not sharing epidemic-related data was not perceived as motivational, but the opposite, some stakeholders felt they needed to take a defensive position to protect their interests.

"*The main pressure to data sharing was coming from WHO headquarters and regional offices…….*"

The tripartite WHO, OIE, FAO One Health collaboration (***Situational enabler)***

The One Health collaboration between supranational organizations at the top level was mentioned to motivate and create a platform to support One Health collaborations at the national levels. Examples of activities supporting this top-down One Health approach was the promotion of training, conferences, and even integrated fund raising for joined research and response strategies. Even though this was experienced as enabler, it has to be mentioned that this also was experienced by stakeholders as being "late". Thus, the lack of efficient collaboration and coordination between the tripartite at first, created barriers (*late engagement of the animal health sector* and *difficulties in multi-sectoral collaboration*) for other stakeholders to engage at an earlier stage in integrated data collection and sharing.

"I think later on, so having then meetings with the WHO, OIE and FAO that also took quite some time. … but in the One health setting they could have pushed it differently"

Rigor on the identification and communication of health threats (*Situational enabler)*

This enabler relates to the need of having rigor on declaring and communicating health threats and implementing response strategies, following the principles of risk communication. The main point is to avoid jumping to conclusions and generating false panic and blame. However, such rigor needs to be balanced with the need to take public health action as well as the need to alert the population on possible risks. Stakeholders have different positions on how to balance this rigor dependent on their different interests as highlighted in the previous section on Barriers to data sharing. Therefore, if this rigor delays and/or hamper risk communication, it can also be seen as a barrier.

"*We felt pretty confident in saying that is a zoonosis and the most likely animal it is coming from are camels. Other sectors had pretty strong opposition to that, they had scientific arguments to say why the data was inconclusive... So, we had to tune down the language, basically not being quite specific in our statements and expressing our thoughts."*

Legal framework and authorization process (circle no. 2, Figure 2)

Informal/confidential notification channels under the IHR (*Situational enabler*)

Many stakeholders mentioned that formal notification is performed only for confirmed cases and/or after approval from national authorities, when different interests and priorities of stakeholders (often referred to as economic arguments) also play a role in the decision to notify, which may lead to delays. Many stakeholders indicated that informal contact can be a way of sharing the suspicion of outbreaks/cases and getting support from the international community, without triggering formal notification, but also that this option may not have been known and/or used as often.

"*I think the IHR 2005 have really helped in terms of managing the expectation of countries: what we expect from the countries and what the countries expect from us. The IHR does not only specify variables and that part of the discussion, recently mentioning the public share of data from WHO, but also other mechanisms for sharing sensitive information that WHO would never make public*."

"*We can tell them we have a case and ask what should we do. So they will guide in terms of do these checks and after you do these checks ..... you are ready to send formal report. …And of course WHO is accepting it but they cannot push countries to give us more information sometimes. Sometimes it was not helping them, but they cannot push, they do not have the power for that.*"

In addition, informal sharing through publicly accessible websites (specifically mentioned was the website of the Ministry of Health from Saudi Arabia) were referred as very important source of data during the MERS epidemic. Stakeholders described the sharing of information that was made publicly available thereby even before the release of formal updates in the WHO websites.

"*In countries like Saudi Arabia the cases were reported immediately on their website."*

Formal notification channels for human and animal health (*Situational enabler)*

Although points for improvement for such notification channels were also indicated (lack of clarity and enforcement, late notification channels for the animal sector), such formal notification mechanisms were mentioned to have brought great improvement to the global sharing of outbreak-related data, especially when compared to the time before their implementation.

"*As we mentioned the international mechanisms in place through IHR allow sharing of information, either bilaterally or more widely, it is extremely useful. I remember the period it was not there, it was extremely difficult."*

"To a large extent I think the IHR are reasonably clear and are reasonably well accepted by all or most countries in terms of what ought to be done. There are interpretational issues …. I think the IHR are a framework in which countries have agreed but again it is not something that has enforcement on it, so countries can also choose to

ignore it. They can follow parts of it and then ignore other parts of it and because there really are no penalties to it. In concept it is not voluntary, it is an agreement, but in reality it is."

Ownership rights and interests (circle no. 3, Figure 2)

Respectful collaborative research

Building on the aforementioned principles of reciprocity and capacity building, the engagement of local scientists in research projects and publications, through the clear explanation of the research objectives and how the data will be used, with fair co-authorship and respect for ownership was mentioned as facilitators to data sharing.

"It was an opportunity for the public health colleagues to do some serious publications and they did a very good job, work on linking the virus between animals and humans, and serology tests, and posters to be published in different conferences."

Good example setting

It was mentioned that the openness from members of the research community to share raw data (open access databases) and their preliminary results (through closed meetings) was a motivator for data sharing. The sharing of pre-published data that was further accepted for publication in scientific journals was also a good example that increased the confidence of researchers to rapidly share data for public health purposes, without compromising their chances of future publications (in close relation to the enabler expedited publications).

"*It was reassuring to work with the scientific community that were very enthusiastic to share data with public health importance. I think protection is important to researchers to share data openly without fearing that someone else use it or if the data cannot be used latter on in publications. So that putting data available will not affect future publications*."

In addition, according to study participants belonging to the global and international stakeholders, the transparency from the Qatari authorities in sharing data with supranational organizations and collaborating with international institutes, served as a good example that was further followed by other stakeholders/countries. In particular, it was important in highlighting a win-win situation as well as addressing the fear of negative consequences of data sharing some stakeholders had.

"*Qatar has been instrumental in demonstrating the link of MERS and camels, through the collaboration they had with international research institutes. They shared those results with us prior to publication, and we modified our guidance documents based on that info."*

Transparency and willingness to share from authorities

Since the ultimate decision to share comes from countries' leadership in the affected countries, their transparency and willingness to share plays an essential role. An example of that was the improvement in data sharing from Saudi Arabia over time that, among other reasons, was attributed to the change in health leadership. This is also reflected on the previously mentioned approval, engagement and support from national authorities for collaborations and data sharing.

"*I think that one factor that played a role was the mission of the seniors to remain transparent, so immediately after a case was confirmed it was announced in the media to avoid any panic. It was also communicated to the EMRO, and within the joined team they were working closely with each other and they shared all info on context and lab results. Full transparency was maintained and all info shared. The good team work, sharing the data immediately, working over hours in the weekend, so the flow of information was maintained*."

Expedited publications

The pushing for fast publications from scientific journals of data relevant to outbreak response was mentioned as a facilitator to rapid data sharing. This includes the fast-track reviews of manuscripts as well as the ability to publish data that has been openly released. In this way, data could be shared and used in the public health response and at the same time ownership of scientific findings could be protected.

"So we were sometimes waiting for publications before sharing the data. But you know we have to go through the whole peer-review process, and all the standard rules for publication. But I might say that the journals were doing this quite fast due to the situation of an epidemic."

"And nowadays I think the scientific community also has backing mechanisms to protect scientist in the sense that many of the top journals can have fast track reviews. Basically you can do both: data sharing to save lives and at the same time protect your scientific ownership."

Memoranda of understanding and agreements for sharing such as MTAs (*Situational enabler*)

Data sharing agreements such as Memoranda of Understanding and Material Transfer Agreements (MTAs) facilitate sharing because they bring legal clarity on obligations and rights from the different Parties, addressing concerns of ownership and sovereignty rights. This clarification of rights and obligations were mentioned to raise trust and confidence of stakeholders for (rapid) data sharing. However, when negotiated during a public health emergency, those can also bring delays in sharing, as identified in the root-cause analysis of barriers. Therefore, in order to benefit the best from this contractual tool for data sharing, pre-established agreements and/or existing models can help to speed up the process and support fair and timely sharing.

"Agreements on confidentiality, shipping, notification are very important to define ownership and notification duties, especially when the data/samples are shared abroad."

Practical aspects of data collection, production and release (Inner circle no. 4, Figure 2)

Support from Supranational and International institutes for national capacity building

Support for field data collection, analysis and sharing through guidance, availability of tools, field investigation teams, training, and data sharing agreements (MTAs) were mentioned as important motivators for data sharing that build on the aforementioned principle of reciprocity. Such support for outbreak response is not only essential for low-capacity countries but all countries, which do not always have the expertise and experience for dealing with unknown or unexpected EIDs.

"*In terms of trust improving over time, I think it was a two way street, there were lot of very good academic groups supporting the member states, providing assistance that may not exist in that country, or at least enhancing the technical capabilities of the affected countries with the input of the technical groups…….*"

Integrated response strategies with the endorsement of national authorities build trust on the response system

Building from the previously mentioned support and approval from national authorities for collaborations and data sharing, at the Qatari national level, the endorsement of field data collection by both ministries (animal health and public health) helped in communicating one strong message building trust among the population. The establishment of the joined investigation team was mentioned as an essential team effort that consisted of experts from the public health and animal health sector, which helped removing traditionally existing barriers for data sharing between both sectors. This broader representation of stakeholders helped in addressing and showing understanding about the concerns of camel owners (fear of killing their camels and/or loss of income), clearly communicating the public

health importance of field data collection, and collaborating with community associations (camel race) for support of field data collection.

"*From the beginning we had a good support from the royal family and the local hospital, and they supported our field investigation and approved the testing and studies. They were supportive of collecting and sharing samples with international research institutes and WHO... We had an uncertainty about the source of the virus, so we tell them (camel owners) about the uncertainty and express that we want to protect their camels*."

International scientific meetings

As mentioned, building trust and opportunities for further collaborations through face-to-face meetings are important motivators to data sharing. International scientific meetings were examples in this regard, being referred as a good platform for sharing publications and up to date information, helping stakeholders to identify current status of knowledge and knowledge gaps.

"*These events allowed us to understand the dynamics of this new disease… and to understand the potential of animal transmission… Another gain from these meetings is that we put the national authorities together with the research institutes and they start to collaborate among themselves… Thanks to this collaboration the ELISA test was produced, more in depth research on camels was done, vaccines started to be worked on*."

Lessons learned and recommendations

Six main lessons were drawn from the stakeholders' experiences, and enablers and barriers. First, the importance of building and maintaining trust between sharing parties, based on a respectful collaboration, whether or not formalized through agreements governing data sharing. Second, the importance of bilateral data sharing and reciprocity of data sharing for sharing parties. The reciprocity of data sharing should be reflected in, amongst others, the assignment of ownership rights over data, in fair recognition of contribution to publications coming out of the data, and in capacity building. Third, the importance of inclusive inter-sectoral and One Health collaboration, based on a pre-organized stakeholder engagement with pre-defined roles and responsibilities of the stakeholders involved. Fourth, the need for the creation of a One Health preparedness and response system that fits all zoonotic EIDs with appropriate supportive technical infrastructure as well as pre-defined access rights and responsibilities of stakeholders. Fifth, the importance of having trusted international collaborating partners as external advisor and reference centers. Such international support for outbreak response is not only essential for low-capacity countries but all countries, which do not always have the expertise and experience for dealing with unknown or unexpected EIDs. Finally, barriers are highly interconnected in a multi-layered system of sharing, and therefore complex to solve. Therefore, addressing these barriers requires solutions that take into account the complexity and multitude of root causes that cause these barriers as well as how these barriers are reflecting upon each other on global, international and national levels of data sharing.

These main lessons learned provided the basis for the recommendations that are specified below, which were categorized in recommendations to i) improve capacity and training, ii) create pre-established infrastructure and systems for data sharing, and iii) capitalize and build forward on pre-established collaborations based on trust and fairness of sharing. For each of the specific recommendations, the root causes addressed by these recommendations are provided.

Capacity building and training

To improve capacity and training to deal with and facilitate data sharing of (re-)emerging zoonotic EIDs in a One Health approach on an international as well as national level, the following seven recommendations were drawn from this case study.

1. Training in interdisciplinary approaches to support experience and ability to work in a diverse team, at field and senior levels, and raise awareness on the importance of data sharing for outbreak response and research at the national level. Training programs should be endorsed by WHO, OIE and FAO. Training should be included in the curriculum of health and veterinary sciences.

Addressing root causes:

- Different interests, priorities and mandates of stakeholders involved
- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Gaps in preparedness of authorities for unknown zoonotic EIDs

2. Create a funding structure among animal health and public health ministries to support investigation of zoonotic diseases and prioritize and implement capacity building for detection, tracking and integrated surveillance.

Addressing root causes:

- Insufficient investment in the animal health sector
- Different interests, priorities and mandates of stakeholders involved and competitive pressure
- Gaps in preparedness of authorities for unknown zoonotic EIDs

3. Engage social sciences for better understanding social determinates of health, and community engagement in outbreak response. Create awareness and training programs at community level on the importance of data collection and sharing in outbreak situations, also helping to reduce risk behavior.

Addressing root causes:

- Data collection formats do not sufficiently take into account cultural differences
- Cultural, social and economic implications of emerging infectious diseases
- Gaps in preparedness of authorities for unknown zoonotic EIDs

4. Train field investigation team on data collection and sharing, empowering them to take decisions.

Addressing root causes:

- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Insufficient training in sampling handling and shipment
- Hierarchical chain of approvals

5. Improve laboratory and bio-banking capacity at the national level, linked to clinical, public health and laboratory capacity building.

Addressing root causes:

- Gaps in preparedness of authorities for unknown zoonotic EIDs (in outbreak investigation/ surveillance)
- Insufficient investment in the animal health sector
- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs

6. Provide training for shipment of biological materials at the national level. Training programs should be endorsed by WHO, OIE and FAO.

Addressing root causes:

- Gaps in preparedness of authorities for unknown zoonotic EIDs (in outbreak investigation/ surveillance)
- Insufficient training in sampling handling and shipment
- Rigidity of authorities to follow strict time-consuming protocols

7. Raise awareness and train IHR focal points on how to use informal/confidential mechanisms for notification and data sharing under the IHR. Also, empower them to take decisions in time of emergencies.

Addressing root causes:

- Hierarchical chain of approvals
- Concerns about economic consequences and bad reputation
- Insufficiency in guidance and case definitions from IHR and OIE
- Definition of obligations for notification not fully clear and sufficient

Pre-established infrastructure and systems for data sharing

Creating and defining a pre-established infrastructure and systems for data sharing facilitate the data sharing during epidemics and public health emergencies, as it removes barriers that take time to negotiate on. The following seven recommendations will help towards the creation and definition of such pre-established infrastructure and systems.

1. Develop a system for sharing data with selected parties (public health officials, supranational organizations and selected international researchers), so information/data can be shared in semi-confidentiality, not immediately to the public domain. Include all relevant stakeholders in this system, and pay attention to provision of relevant feed-back

Addressing root causes:

- Concerns about economic consequences and bad reputation
- Concerns about commercialization of their samples and lack of reciprocity
- Lack of globally agreed mechanism for data sharing
- Pre-established collaboration insufficient for zoonotic EID outbreaks

2. Clarify transparent obligations for sharing in the system: when, to whom, how and which type of data, how the data will be used, how the analytical results will be discussed, shared and published. Pre-define a minimum set of data to be shared (extended beyond data to be shared under the IHR, standardized One Health approach).

Addressing root causes:

- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Gaps in preparedness of authorities for unknown zoonotic EIDs
- Lack of standardized system for data sharing
- Definition of obligations not fully clear and sufficient
- Concerns about commercialization of their samples and lack of reciprocity
- Importance of publications for reputation and career
- Concerns about consequences and bad reputation
- Different interests, priorities and mandates of stakeholders involved and competitive pressure
- Importance of publications for reputation and career
- Not everyone is capable and able to write publications within days
- Dual role and interests of scientists at public health institutes

3. Developing unified standards and protocols for data collection and sharing, including practical information such as sample handling, shipping, etc. by integrating and extending current ones. Training in and dissemination of such standards and protocols is key, and should be endorsed by WHO, OIE and FAO.

Addressing root causes:

- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs
- Lack of standardized MTAs
- Rigidity of authorities to follow strict time-consuming protocols
- Gaps in preparedness of authorities for unknown zoonotic EIDs
- Pre-established collaboration insufficient for zoonotic EID outbreaks

- Different interests, priorities and mandates of stakeholders involved and competitive pressure

4. Revise criteria for notification and improve formal notification channels based on clarity and specificity, including criteria for unknown diseases, incorporating a One Health approach from the outset and throughout. Provide guidance on how this will work in practice, and work cooperatively with all countries to promote compliance.

Addressing root causes:

- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs
- Gaps in preparedness of authorities for unknown zoonotic EIDs
- Difference in perceived sense of urgency
- Lack of globally agreed mechanism for data sharing
- Different interests, priorities and mandates of stakeholders involved
- Definition of obligations not fully clear and sufficient
- Insufficient authoritive power for enforcement

5. Improve compilation and visualization of global disease outbreak data.

Addressing root causes:

- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs

6. Develop models and/or pre-established agreements for national and international data and sample sharing and biobanking that consider emergency situations and highlight obligations and rights of each party, as users and providers of data, in an equal foot for all countries, independent of the capacity level. Ensure access and benefits are on equal footing by pre-defining reciprocity for data providers. Identify and address challenges regarding the commercial implication of sharing data. Develop guiding mechanism on IPR (issues) with a new emerging pathogen.

Addressing root causes:

- Different interests, priorities and mandates of stakeholders involved
- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs
- Gaps in preparedness of authorities for unknown zoonotic EIDs
- Concerns about economic consequences and bad reputation
- Complexity and difference in countries' regulations
- Lack of standardized MTAs
- Lack of globally agreed mechanism for data sharing
- Concerns about commercialization of their samples and lack of reciprocity
- Importance of publications for reputation and career
- Dual role and interests of scientists at public health institutes
- Rigidity of authorities to follow strict time-consuming protocols
- Complexity and difference in countries' regulations

7. Scientific journals should acknowledge and accept the sharing of pre-published data of importance for public health, and guarantee that this will have no influence in future publications on the data. They

should also make fast track review and open access norm in outbreak situations. Ensure appropriate acknowledgement for data contributors/generators. In the longer term, a change in funding system is necessary to stimulate open access and pre-publication data sharing.

Addressing root causes:

- Importance of publications for reputation and career
- Not everyone is capable and able to write publications within days
- Dual role and interests of scientists at public health institutes
- Lack of globally agreed mechanism for data sharing
- Different interests, priorities and mandates of stakeholders involved and competitive pressure

Pre-established collaborations building on fairness and trust

Supported by the importance of building and maintaining trust between sharing parties and the importance of bilateral sharing and reciprocity of data sharing (reflected in shared ownership, publications, and capacity building), it is essential to capitalize and build forward on pre-established collaborations that are based on fairness and trust. The following four recommendations were identified to help achieving this.

1. Identification and description of best practices for data sharing with good examples of win-win situations in which all relevant stakeholders were involved. Also, document lessons learned from past experiences and the way barriers were overcome.

Addressing root causes:

- Lack of globally agreed mechanism for data sharing
- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs
- Gaps in preparedness of authorities for unknown zoonotic EIDs
- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Rigidity of authorities to follow strict time-consuming protocols
- Concerns of economic and reputation consequences
- Concerns about commercialization of their samples and lack of reciprocity
- Importance of publications for reputation and career

2. Promoting constant meeting between the different stakeholders involved in outbreak research and response, to identify possibilities for action and update each other's plans and progress.

Addressing root causes:

- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Concerns about commercialization of their samples and lack of reciprocity
- Different interests, priorities and mandates of stakeholders involved and competitive pressure
- Hierarchical chain of approvals
- Difference in perceived sense of urgency
- Gaps in preparedness of authorities for unknown zoonotic EIDs (outbreak investigation/ surveillance)

3. Establish a permanent joined (OH) outbreak investigation team, with appropriate authority to share data. This includes investment in a national risk assessment.

Addressing root causes:

- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Different interests, priorities and mandates of stakeholders involved and competitive pressure
- Hierarchical chain of approvals
- Difference in perceived sense of urgency
- Gaps in preparedness of authorities for unknown zoonotic EIDs (outbreak investigation/ surveillance)
- Data collection formats do not sufficiently take into account cultural differences
- Insufficient investment in the animal health sector

4. Establishment of joined priorities and research agenda, representing the interests of all sectors. Start with what does an inclusive and One Health approach mean, how will it work best and what is the added value.

Addressing root causes:

- Pre-established collaboration insufficient for zoonotic EID outbreaks
- Different interests, priorities and mandates of stakeholders involved and competitive pressure
- Insufficient investment in the animal health sector
- Gaps in preparedness of authorities for unknown zoonotic EIDs (outbreak investigation/ surveillance)
- Importance of publications for reputation and career
- Dual role and interests of scientists at public health institutes
- Current data sharing systems insufficiently standardized and prepared for unknown zoonotic EIDs

Annex I Literature database

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Annex II Interview guide

Introduction

Based on your experience / the experience of your institute as… (*what we know about his/her involvement with MERS-CoV*)… during the MER-CoV epidemic (in Qatar); we are contacting you to learn about your experience and opinion on the sharing of data during the epidemic. Before starting I would like to highlight that this interview will be performed according to the Chatham House rules, therefore the information provided will be kept anonymous. We will report to you the preliminary findings from the study for feedback and validation purposes. Also, would like to ask your consent to record this interview for further analysis and use, anonymously, in future publications. Is there any point that you would like to clarify before starting the interview?

Questions

1. Confirming stakeholder role and contribution

Introduce and explain the timeline and use it as an active tool during the following questions.

a) In the invitation letter to this interview, we have described, based on the desk study, how we identified your involvement with the MERS-CoV research/response. Could you shortly confirm or correct your role and task to that, especially in regard to your participation/collaboration with the MERS-CoV research/response in Qatar?

Useful tools for these questions

- *Timeline displaying the key developments/evolvements of the epidemic and highlighting the involvement of the stakeholder and his/her institution on the MERS-CoV research/response.*

2. Description of data sharing practices

Introduce and explain the interview data matrix and use it as an active tool during the following questions:

a) What are your general feelings about the data sharing practices during the MERS-CoV epidemic? From your experience, during the course of the epidemic, do you think sharing was overall satisfactory on unsatisfactory?

b) Which types of data were typically shared with you and from whom were they coming? Did this differ in the different phases/periods of the epidemic (see the timeline)?
   - Points for confirmation: how he/she obtained the data and how the data was used

c) Which type of data were typically shared by you and towards whom did you share these? Did this differ in the different phases/periods of the outbreak (see the timeline)?
   - Points for confirmation how he/she shared the data and why he/she shared (perceived importance of the data)

d) Did you - generally speaking and as far as you can see - notice any change in attitude towards data sharing over time, or did you yourself change or had to change your data sharing practices or policy over time? If any changes, can you elaborate on the perceived or suspected motives?

Useful tools for these questions

- *Interview data matrix discriminating and exemplifying the different types of data, the different levels of sharing and the different stakeholders involved in each level;*

- *Timeline discriminating the different phases and events that occurred in each phase in order to compensate for recall bias.*

3. Enablers to data sharing

a) You have just described some events during the epidemic in which either you shared data or data was shared with you. In your opinion, what were the facilitators, or in other words the enablers, that helped or improved the sharing process the most?
   - By enablers we mean any factor that facilitates or motivates data sharing. Those can be conditions, procedures, attitudes, persons, infrastructures, technologies, etc.

b) Depending on one's position in an organization one might have different views on the possibilities for influencing data sharing. From your personal opinion, are you or your organization in a position – formally or informally – to enforce or facilitate the sharing of outbreak-related data?

Useful tools for these questions

- *Definition and examples of enablers;*
- *Timeline discriminating the different phases and events that occurred in each phase in order to compensate for recall bias.*

4. Problems and complications / Barriers to data sharing

a) Changing the topic from enablers to data sharing to possible complications and barriers. From the data that you described was shared with you, did you encounter any serious issues, that did endanger or delay, or could have endangered, the application/use of the data for the epidemic response and control? Concerning:
   - The quality or completeness of data?
   - The timeliness of sharing?
   - Differences on perceptions (the perceived urgency)?
   - Procedures or authorization of the sharing?
   - (Interpretation of) the legal framework regarding national/international sharing?
   - Any other?

b) To make sure that we have a complete overview of possible experienced complications to the sharing of data we ask all interviewees specifically: was there for you at any point in time a need to access specific data that was not available or accessible for you; and which was not yet mentioned in this interview? If so, what type of data was it and why do you think it happened?
   - Did you finally managed to overcome this barrier and have had access to the data? How did you do this and how long did it take? How the data would have contributed to the epidemic research/response?

c) Now changing the perspective from receiver of data to provider, have you been in the situation that you or your organization were/was reluctant to share data or had to decide not to share? Was this temporally or definitely? Can you elaborate on the motives?
   - Did you find a way to overcome these barriers and if so, how?

Useful tools for these questions

- *Definition and examples of the different types of public health actions for outbreak control and response;*
- *Interview data matrix discriminating and exemplifying the different types of data, the different levels of sharing and the different stakeholders involved in each level;*

- *Timeline discriminating the different phases and events that occurred in each phase in order to compensate for recall bias;*
- *Definition and examples of possible barriers.*

6. Proposed changes and recommendations

a) We do not finish this interview, without giving you the opportunity to express your final reflections on the experience with data sharing during the MERS-CoV epidemic. In this regard, have you identified any lessons learned (regarding data sharing) that could be useful for future epidemics? Which advices can you give to others in similar/future situations?

b) We all know that there are no clear/easy solutions to address all data sharing challenges. But, do you see any (other) possible solutions or what would be a first step forward in solving these challenges?

    - Point for confirmation: who could/should work towards developing/implementing these suggestions? Who should take up the responsibility?

Conclusion

Thank you very much for your time. Your contribution is very important for our research. Could we contact you again in the future to provide our preliminary results for feedback and validation? Could you recommend one or more persons who we could take up contact for our research?

Annex III Timeline of events during the MERS-CoV epidemic

COLOR CODING

Information related to the Food sector

Information related to the Animal Health sector

Information related to the public health sector

Information related to Qatar

ACRONYMS

Pnº *Patient nº*

QPnº *Qatar Patient nº*

UK *United Kingdom*

CoV *Coronavirus*

nCoV *New coronavirus*

EMC *Erasmus Medical Center*

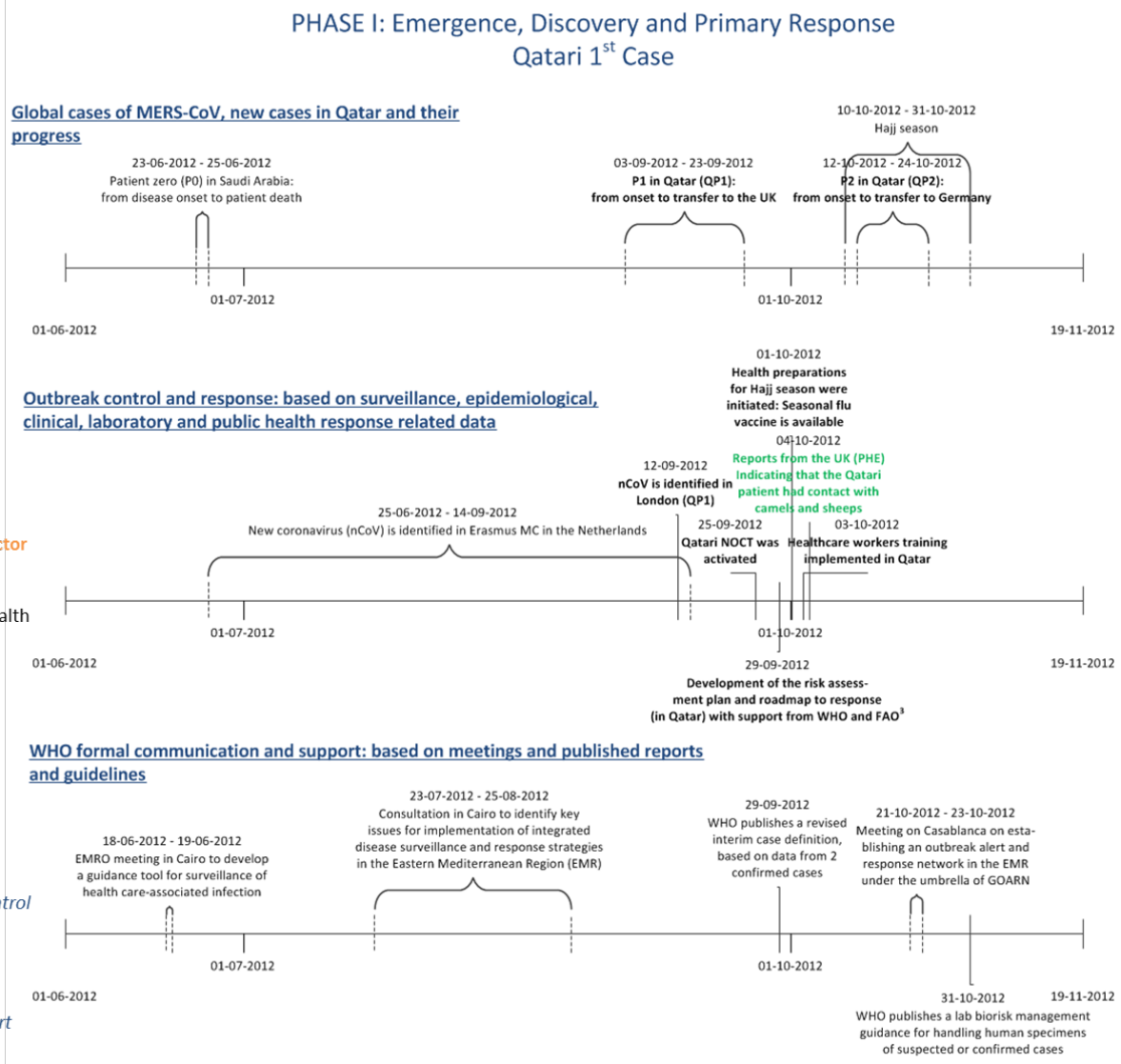
PHE *Public Health England*

NOCT *Qatari National Outbreak Control Taskforce*

EMR *Eastern Mediterranean Region*

EMRO *WHO Regional Office for the Eastern Mediterranean Region*

GOARN *WHO's Global Outbreak Alert and Response Network*

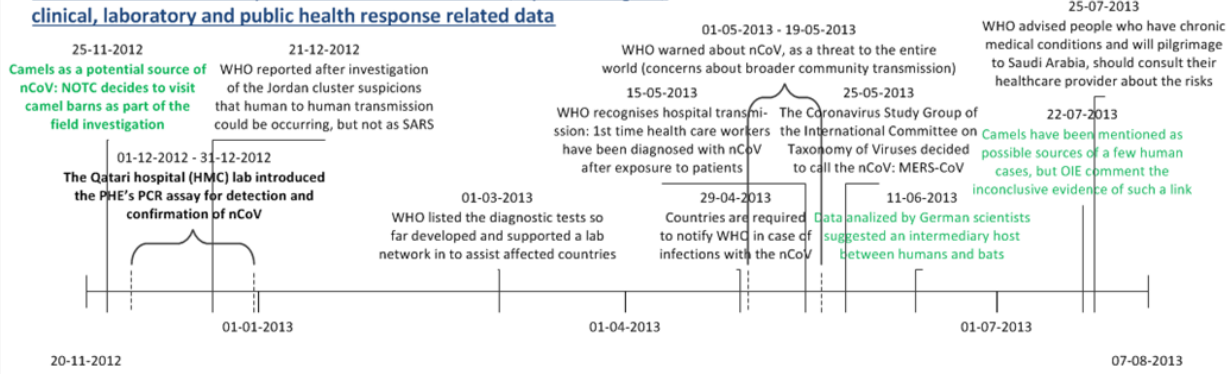


PHASE II: Mitigation and Understanding

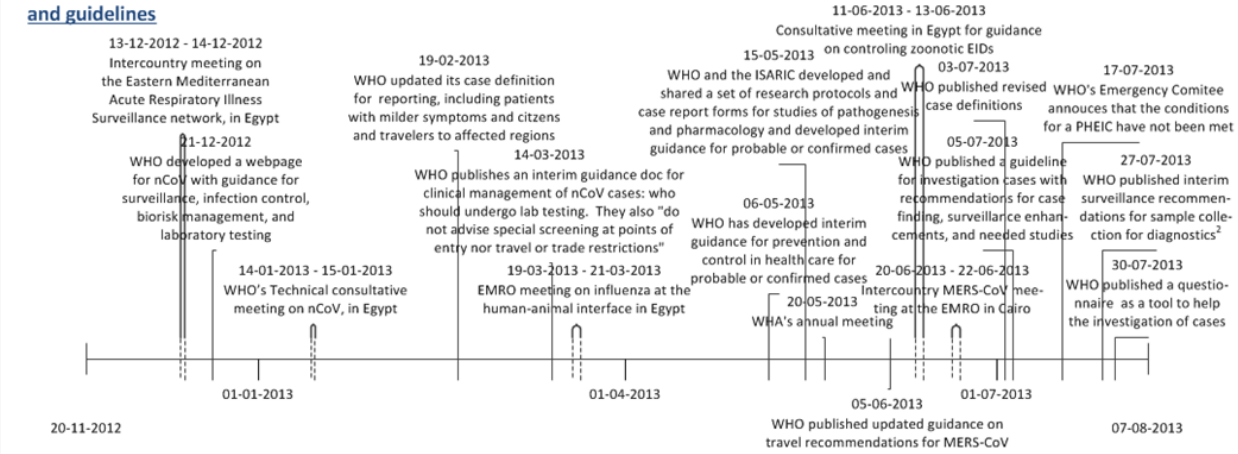
a) Increasing number of cases and deaths in the EMR, with confirmation of Qatari 2nd Case

Global cases of MERS-CoV, new cases in Qatar and their progress

Outbreak control and response: based on surveillance, epidemiological, clinical, laboratory and public health response related data



WHO formal communication and support: based on meetings and published reports and guidelines

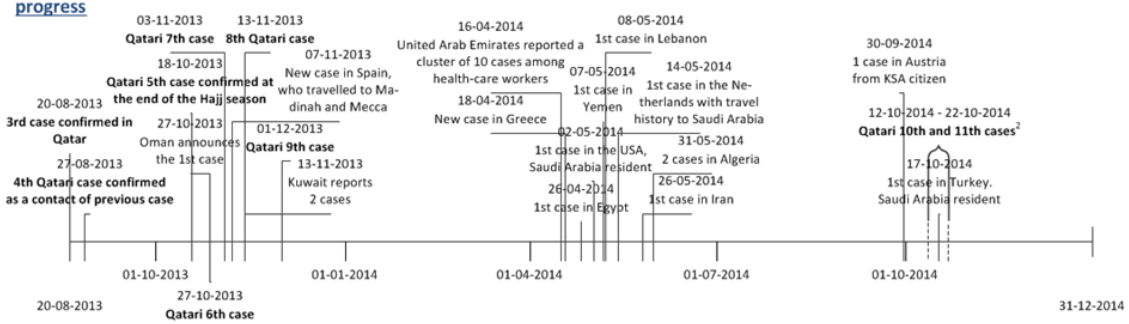


ACRONYMS

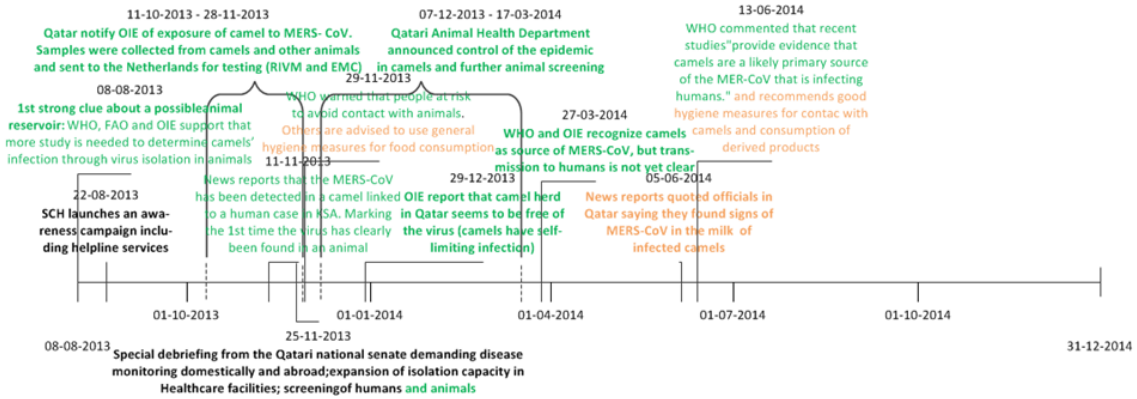
HMC *Hamad Medical Corporation*
SARS *Severe Acute Respiratory Syndrome*
MERS *Middle East Respiratory Syndrome*
ISARIC *International Severe Acute Respiratory and Emerging Infection Consortium*
WHA *World Health Assembly*
PHEIC *Public Health Emergency of International Concern*

PHASE II: Mitigation and Understanding
b) Isolation of the virus in camels, and continuing cases from Qatar

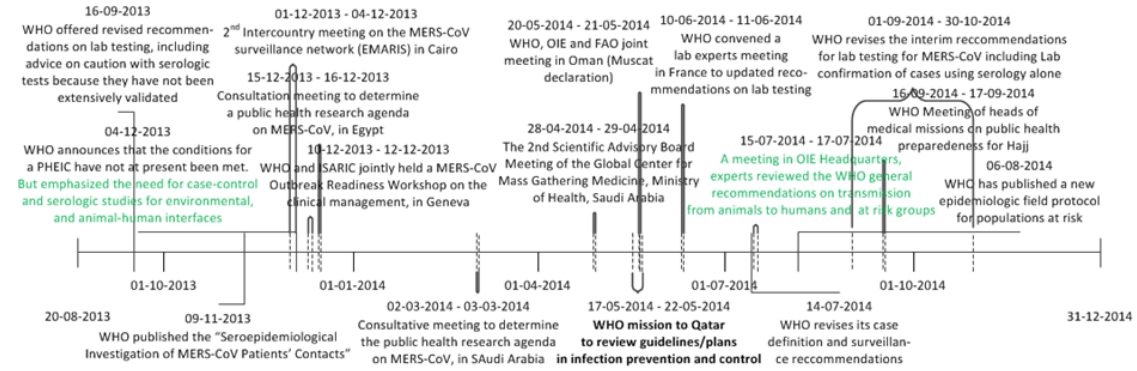
Global cases of MERS-CoV, new cases in Qatar and their progress



Outbreak control and response: based on surveillance, epidemiological, clinical, laboratory and public health response related data



WHO formal communication and support: based on meetings and published reports and guidelines

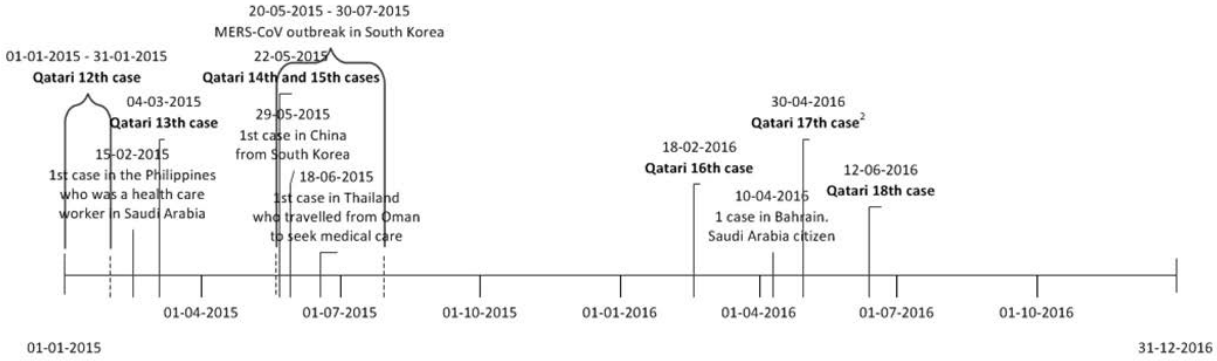


ACRONYMS

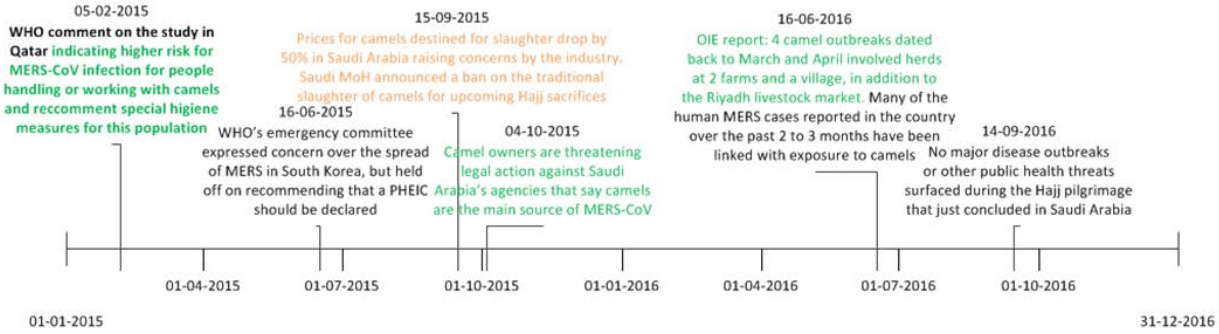
SCH *Qatari Supreme Council of Health*
RIVM *Netherlands Institute for Public Health and the Environment*
EMARIS *Esatern Mediterranean Acute Respiratory Infection Surveillance*

PHASE III: Disease Spreap and Knowledge Gaps

Global cases of MERS-CoV, new cases in Qatar and their progress



Outbreak control and response: based on surveillance, epidemiological, clinical, laboratory and public health response related data



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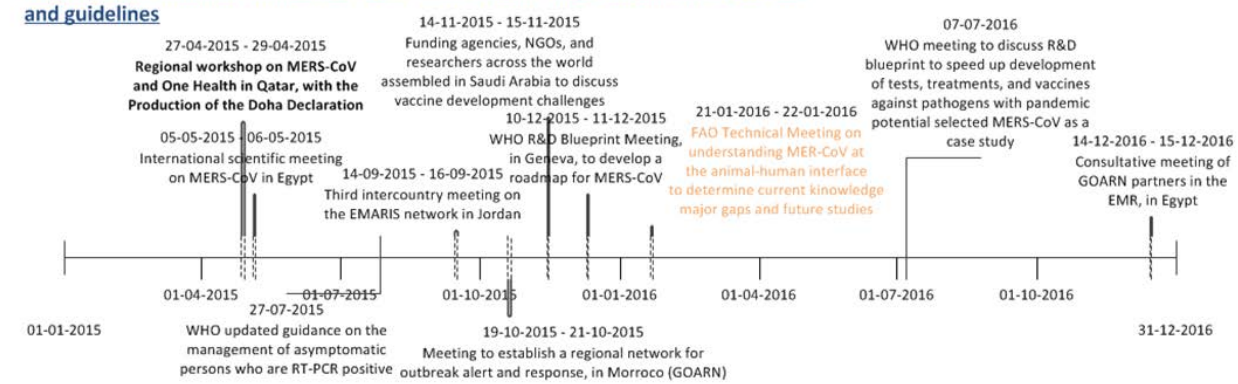
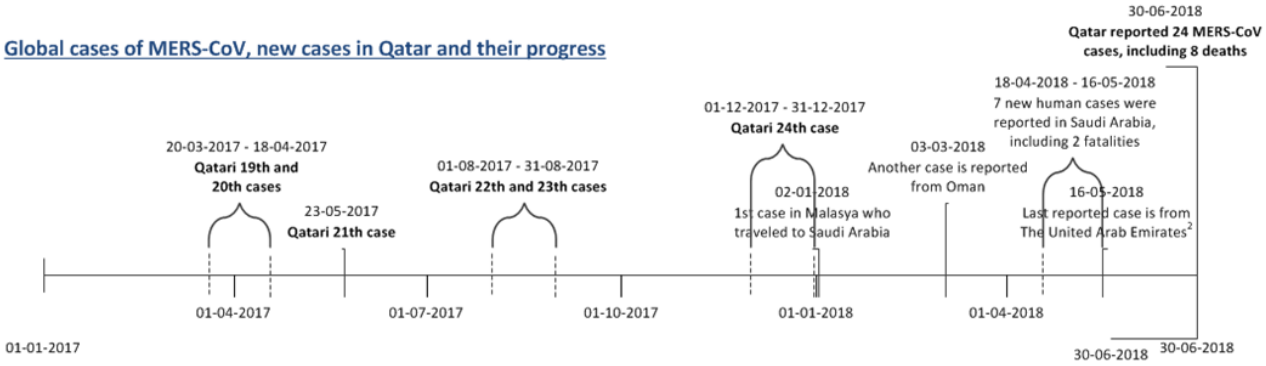
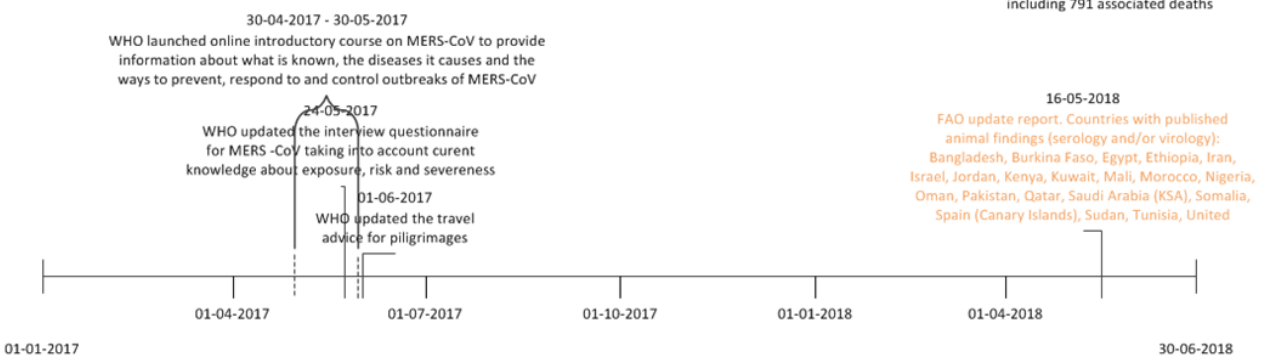
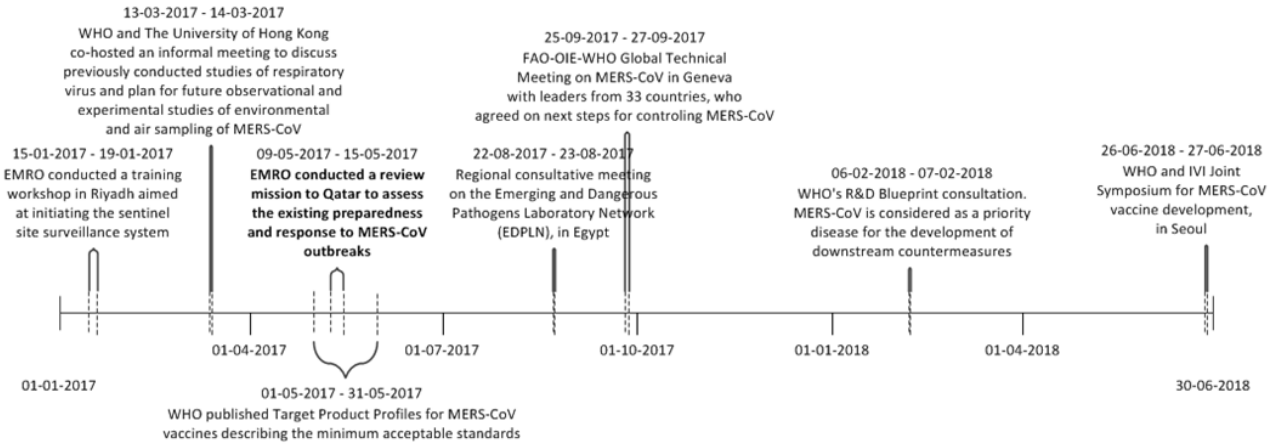


PHASE IV: Reflections and Lessons Learned

Global cases of MERS-CoV, new cases in Qatar and their progress



Outbreak control and response: based on surveillance, epidemiological, clinical, laboratory and public health response related data



WHO formal communication and support: based on meetings and published reports and guidelines