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Data sharing: a cholera case study

Final report

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1. Introduction

"The accessible sharing of timely, quality and appropriate research data (defined below) has been identified as a key component of epidemic preparedness. Increased availability of data can enhance the global community's ability to effectively respond to, coordinate and manage response strategies for disease outbreaks. Wellcome and other research funders are working together through a network called GloPID-R to 'strive to make data accessible to each other and to the relevant research community as rapidly as possible, and with minimal restrictions'. There is little information available on how researchers and organisations share data, the extent to which these data are used and whether the data is of the quality or format needed to be usable and useful in answering critical questions to advance knowledge and inform decision-making related to the response," (Wellcome Trust's Request for Proposal).

The accessibility and sharing of research data among stakeholders at the global, regional and field level is essential for ensuring the preparedness and response to infectious disease outbreaks. This is particularly true in cases of pathogens that cause explosive epidemics, such as *Vibrio cholerae.* Cholera still affects at least 47 countries, resulting in an estimated 2.9 million cases and 95,000 deaths per year worldwide (Ali & al. 2015). Cholera affects the poorest and most vulnerable populations with low access to safe water and basic sanitation.

During outbreak, the biological isolates are analysed to confirm their epidemic potential, and engages the response. From a longer research perspective, isolates and associated data help to identify whether toxigenic *vibrio cholerae* can establish environmental reservoirs, or if cholera transmission is exclusively inter-human. A recent phylogenetic study using all available African isolates and associated data (Weill et al. 2017), including anti-microbial resistance findings, suggests that Africa cholera epidemics rely on inter-human transmission only. This should have tremendous implications for prevention and response strategies. The roots of transmission are reconstituted, with these results combined with epidemiological data on hotspots. Pin-pointing the hotspot areas where most cases of cholera occur makes the control target achievable, because the at-risk population target for interventions is lower. The identification of antibiotic susceptibilities also directly contributes towards determining antibiotic treatment strategies, in addition to rehydration, which is the cornerstone of treatment for cholera. Current evaluations use these data, combined with epidemiological and clinical data on household risk factors of cholera, to determine whether the use of antibiotic administration might be a potential curative, or even preventive, strategy. In addition, the evaluation of intervention strategies (both WASH and vaccine campaigns) based on clinical data, epidemiological data and behavioural studies, opens new possibilities for control strategies. These research findings all support the newly established 2030 roadmap for ending cholera (Global Task Force on Cholera Control 2017), which states that when combined, the hotspot mapping and OCV use are key for controlling 90% of Cholera.

These areas of research draw on several data that are produced, transmitted, transmuted, and analysed. These have been circulated across levels and individuals who contribute to data processing for research.
At a first stage, these data are:

- Biological samples (stool), derivates (isolated vibrio strains and their genetic signature), and data related to the lab analyses of the samples
- Standardised case report forms / clinical data forms /biological report forms
- Clinical databases, epidemiological line lists and surveillance databases
- Field data for the vaccine coverage survey
- Observations, interviews or questionnaires for behavioural analysis

To design our interview guidelines, we pre-identified 4 levels of data production and 3 transmission nodes:

- Between the sub-national and national level: clinical/biological and surveillance data to confirm that first cases are the starting point for outbreak declaration and research.
- Between the national and regional level: Sharing data within a region is essential to understand how epidemics spread and define response strategies.

- Between the regional and the global level: Meta-analyses on outbreak dynamics assist with preparedness and response plans at national, regional and global levels.

Whether due to scientific, political, communication or economic issues, impeding the sharing of timely, quality data can greatly impact on the relevance of research orientations and appropriate decision-making in the field. This study aims to better understand the barriers and enablers for research data sharing during recent epidemics of cholera in Western Africa. It takes into consideration the experiences at a country level from outbreaks in Guinea and Côte d'Ivoire in 2012 and 2014 respectively, as well as the region's general experience up until 2018, to gather specific and general lessons learned.

The first outbreak chosen for this case study is the 2012 Guinean cholera outbreak. This became emblematic in the cholera field for using an Oral Cholera Vaccine (OCV) for the first time ever in a reactive mass campaign in Africa. This feat was even more impressive when considering it was carried out in hard-to-access areas of one of West Africa's most economically disadvantaged countries. Guinea could, however, rely on a nexus of other positive drivers for data sharing and innovative interventions, which are presented below.

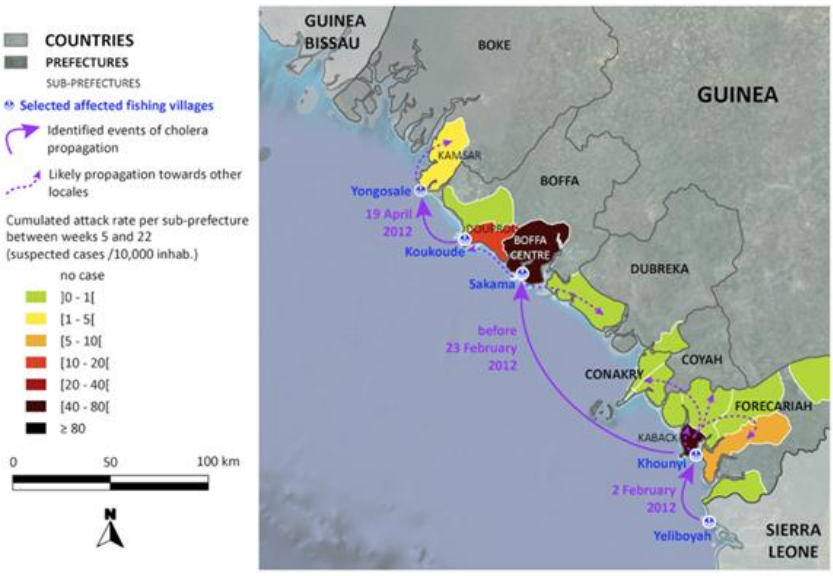

Figure 1 Cholera in Maritime Guinea between February and May 2012 (Rebaudet et al. 2014)

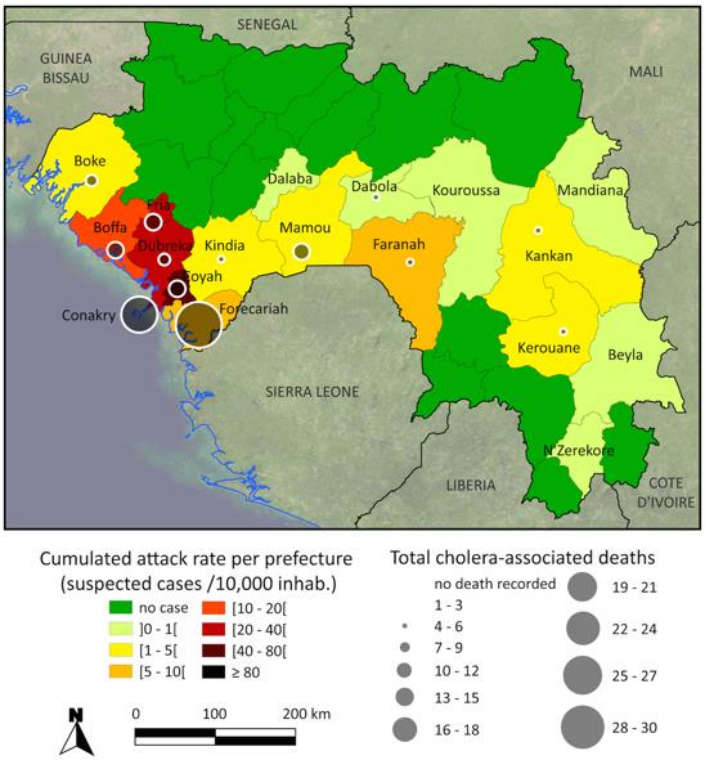

Figure 2 **Cumulated cholera attack rates and deaths per prefecture during the 2012 Guinean epidemic (Rebaudet et al. 2014)**

Prior to the outbreak of 2012, Guinea's Ministry of Health received integrated technical support for cholera surveillance from the Africhol consortium (AMP program with BMGF funds). This allowed year-round enhanced case-based surveillance, combining clinical, biological and epidemiological data (Blake et al. 2018). When the outbreak was detected in early February 2012, Médecins Sans Frontières was already operational in Guinea, and able to rapidly provide medical support in cholera treatment centres. With Epicentre, they provided data management tools including standard line lists with a localization of patients. The Africhol Programme funded an outbreak investigation in Kaback Island, and enhanced surveillance zones were extended to Boffa and Forecariah regions for the duration of the outbreak. MSF also proposed to implement a protocol to evaluate innovative tools for cholera confirmation (rapid test), in partnership with the Institut Pasteur in Paris (Martinez-Pino et al. 2012). The university of Aix Marseille sent a PhD student to support a retrospective outbreak investigation in coastal areas, which was completed with a phylogenetic study that compared strains isolated in Guinea and Sierra Leone in early 2012 (the Guinean strains had been collected by the INSP with Africhol funding) (Rebaudet et al 2014). For these programs, materials transfer agreements or conditions for data access had been already discussed and signed with the Ministry of Health, and the country Focal Point was strongly involved in surveillance activities when the outbreak occurred. WASH non-governmental partners, who were also in the country, rapidly contacted the cholera treatment centres to gather data to identify hotspots and target their interventions.

At a global level, MSF Suisse led discussions to convince regulators (WHO) about the interest of implementing the first OCV reactive campaign, which was implemented in the Forécariah and Boffa regions in 2012. Evaluations of the feasibility, acceptability, vaccine effectiveness and safety were conducted during this campaign in response to WHO concerns about OCV use (Luquero et al. 2012, Ciglenecki et al. 2013,

Luquero et al. 2014, Grout et al. 2015, Azman et al. 2016). In parallel, Guinean clinicians in the University Hospital of Donka were prepared to implement a fundamental research protocol on cholera and pregnancy (Sako et al. 2016) to inform future responses. Researchers from universities and research institutes from abroad worked on more general questions about cholera transmission through water or human-to-human transmission by collecting samples and epidemiological data used in meta-analyses (Rebaudet et al. 2014, Moore et al. 2018).

The second case is the 2014-2015 Côte d'Ivoire outbreak, which has attracted only little attention with few institutional collaborations on data production and sharing. With national and international stakeholders, we explore the barriers for data sharing and innovative responses to this outbreak.

Figure 2 Ivorian districts affected by the 2014-15 cholera outbreak. Source: 2015 Africhol Consortium meeting, Lomé, Togo

Côte d'Ivoire was a partner involved in the Africhol Consortium and received financial and technical support for cholera surveillance. Although there is no case reporting on the WHO database for 2014, the Ministry of Health notified the outbreak on October of this year. A multi-agency proposition to organize a reactive OCV campaign failed due to constraints in terms of available doses, political sensitivities in choosing target groups, a lack of advocacy on OCV as a control tool and competing priorities from the neighbouring Ebola outbreak. The surveillance and laboratory data produced during the outbreak were used for classical epidemiological monitoring but did not lead to specific institutional sharing or new interventions. So far, in terms of publications the data have only been exploited in meta-analyses (Smith et al. 2015, Sauvageot et al. 2016, Weill 2017). National researchers published surveillance data from past outbreaks (Dosso et al. 1983, 1984, 1998, Ekra et al. 2009), anti-microbial resistance (Kakou N'douba et al. 2012), and environmental surveillance (Lanusse 1987, Adingra 1998, Lowenhaupt 1998, Tiekoura 2010, IPCI 2012, cited in Rebaudet 2012).

Table 1 Type of data shared during outbreaks

Type of data production method	Information	Used during outbreak	Source	Guinea Outbreak		Côte d'Ivoire Outbreak	
				Produced	Shared and used?	Produced	Shared and used?
Case based surveillance and outbreak investigations	number of cholera cases (suspected and confirmed)	Triggers alert Biological sampling and testing. Epidemic curve Outbreak alert in neighbouring areas	Health care centres (HCS), CTC, District officers, Reference laboratory, MoH with support from the Africhol program	Yes, in CTC	Yes, open access	Yes, in CTC	Yes, restricted access and used for targeted intervention
	Location area of the case & contacts	Cluster detection and household WatSan interventions					
	age, gender, clinical outcomes	Dynamic of transmission, risk factors					
Vaccine coverage	Proportion of fully vaccinated within target population	Evaluating achievement of target population	MoH data collection team, Ministries of Health, WHO, MSF, Epicentre	Yes, MoH & MSF staff	Yes	No (no OCV campaign)	No (no OCV campaign)
Vaccine effectiveness	Influence of the intervention on the case count (surveillance dependant)	Evaluating the control value of the intervention	MoH data collection team, Ministries of Health, WHO, MSF, Epicentre	Yes, MoH & MSF staff	Yes	No (no OCV campaign)	No (no OCV campaign)
RDT (rapid diagnostic tests)	Detection (VC O1/VC O139)	Rapid and easy identification Trigger outbreak alert Specimen sent to reference lab	MSF, Epicentre/ Institut Pasteur Dove (JHU)/Africhol	Yes	Yes, Epicentre-Institut Pasteur	No Yes	No Yes
Cell culture data	Case confirmation (VC O1/VC O139)	Outbreak confirmation	National Reference laboratory	Yes	Yes	Yes	Yes
	Antibiotic susceptibility	Case management of severe cases					
	Subtyping	Outbreak dynamic					
	Detection of VC O1/VC O139 in environmental samples	Environmental early warning	National Reference laboratory, John Hopkins,	No	No	Yes in IPCI,	Yes, some but not all
PCR data	Case confirmation (VC O1/VC O139)	Outbreak confirmation	National Reference laboratory provides the samples and regional laboratory makes the PCR	NA	NA	NA	NA
Genotyping data	Genotyping/PFGE	Outbreak dynamic (origin, expansion/country, global)	NICD, SA/Africhol	Yes	Yes	Yes	Yes
	Whole genome sequencing (WGS)	Genetic evolution and emergence of new strains	Welcome Trust Sanger Institute (WTSI), Cambridge UK /Africhol /Institut Pasteur	Yes	Yes	Yes	Yes
		Antibiotic resistance genes		scheduled	scheduled	scheduled	Scheduled
Cultural epidemiology data	KAP (knowledge, attitudes and practices)	Measuring pre-defined indicators on health practices	Ministries of Heath, WHO, MSF, Epicentre	Yes	Yes, Epicentre	No	No

Stakeholders involved in research and the public health response before and during cholera outbreaks contributed to multi-level data production, collection and analysis. This case study aims to document research data sharing during outbreaks due to one known pathogen with licensed intervention (cholera), to provide accurate knowledge about the reasons and conditions for timeliness, accessibility, transparency, quality and PEARLES (Political, Ethical, Administrative, Regulatory, Logistic, Economic and Social) barriers for data sharing across the subnational, national, regional and international levels.

The report is structured to

- Present the study design and methodology
- Present the study participants' characteristics
- Report the study participants' opinions on the 5 key questions of the RFP
  - To what extent did data sharing occur during the outbreak? What types of data were shared? How did this help inform the public health response?
    - Timeliness is defined in this section
  - What were the key barriers to data sharing that were encountered?
    - Issues about accessibility, quality, discoverability, fairness, equity, and transparency are shared depending on their importance for study participants
  - What were the key enablers to data sharing and how did they help the process?
  - How could greater availability of data have enhanced the response?
  - Of the lessons learned about enablers for data sharing, which are generalizable?
  - Who is responsible for implementing any proposed changes based on lessons learned?
- Synthesize the findings in a table of the PEARLES barriers, enablers and suggested leverages
- Start discussion about leverages and next steps in the conclusion

2. Study design

Study type

This is a multi-level case study using in-depth interviews and a concise literature review to document and analyse the practices and perceptions of stakeholders involved in research (producing and analysing surveillance, laboratory, and social sciences data) about the preparedness and response to Cholera outbreaks.

Ethics

- Information notice and consent forms have been shared with participants and signed before interview.
- Letters of authorization to conduct the study have been sent to the national laboratory of references and surveillance direction in Côte d'Ivoire and Guinea, with approval received by email or phone.
- National IRBs of both Côte d'Ivoire and Guinea approved the study protocol.

Methods

Participant selection

Study participants were identified using a mixed approach: the purposive sampling approach (mapping by literature review and pre-selection based on brainstorming with team members involved during cholera outbreaks), and planning of interviews by convenience (availability and willingness to participate in the study).

- Mapping of stakeholders provided the names and contact of 42 stakeholders (institutions or individuals) who have worked on data produced in Côte d'Ivoire or Guinea. Among these stakeholders, 22 work at global level, 10 at regional level, 5 at national level in Côte d'Ivoire and 5 at national level in Guinea. In total we expected to interview 5 of the most published/cited stakeholders at global level and 3 at regional level.

- Additional criteria to send the invitation were: expertise, direct involvement in data sharing processes, public expression of concerns about data sharing processes during formal and informal meetings that were reported by the study team members.
- In the protocol, it was planned to ask the first participants to suggest at least three other relevant stakeholders to be interviewed (15 names and contact details) at global, regional and country level, who might have other viewpoints or experiences. In practice, names occurred during interviews when talking about partnerships and the demand for names was not prompted nor standardized.

In-depth interviews

Of 22 invitations to participate in the study, 14 were accepted, 8 received no answer, and none was refused. Global and regional interviews were conducted immediately after the protocol was finalized. Interviews with national stakeholders were conducted after national IRB approval in Côte d'Ivoire and Guinea.
All study participants signed a consent form prior to their interviews.
We conducted face-to-face interviews with 5 stakeholders, and other interviews over the phone or skype using video-conferencing when technologically possible (2).
The flow of interviews was as follows:

- The interviewer presented the study. The instruction notice, and consent form were already shared at this stage.
- The study participant was invited to introduce his/her experience of research during cholera outbreaks (projects, aims of the projects, expertise, partners)
- The study participant was invited to share his/her experience of data sharing at each stage
- (The interviewer checks the memo during the interview and suggests additional questions if not spontaneously treated by the study participant (see the memo in the appendices))
- The study participant was invited to share recommendations for improvement of data sharing practices.

NB: tentative flowcharts were designed in the protocol to map the whole picture of data sharing processes. It was planned to share these flowcharts with the study participants to collect their comments about the bottlenecks for data sharing and their proposed solutions to improve data access. In practice, during the first interviews these flowcharts were overly confusing, which led to a general discussion about the considerations. We decided to focus on the study participants' own experiences and positions to specify lessons learned.
The analysis approach was:

- Interviews were recorded.
- Interviews were transcribed by transcriber consultants and archived in a password-protected computer.
- Using Dedoose, a Computer Assisted Qualitative Data Analysis Software (CAQDA software), each anthropologist proceeded to the analysis of each interview transcript (15 in total).
- A sample of the transcripts (the first 3) were double-coded to test inter-rater reliability, measured using Cohen's kappa coefficient (κ). The anthropologists discussed their definition and application to reach consensus and assure coding consistency.
- A predefined codes structure for analysis was designed based on the main areas of interest of the Request for Proposal. During the second phase of analysis, new codes were added following consensus among anthropologists, based on interview contents.
- Using the database of stakeholders with an indication of project involvement and connections and based on the common involvement of stakeholders in the same project, the interview transcripts for coding were analysed by the same anthropologist.
- When relevant and possible, quantitative trends on the main areas of interest of the RFP were extracted from information collected on the CAQDA software.

Concise literature review

A concise review of the published literature and protocol for data sharing was done at three stages of this study:

- To map the key research teams and stakeholders to be included in the study

- To prepare in-depth interviews by reviewing the study questions, type of data and findings of each study participant, and identify his/her research networks
- To inform key indicators listed in the protocol to answer the RFP questions

The annotated bibliography is presented in a specific document. Results of the analysis of the literature using the same coding trees as for interviews is presented in the result section of this report, vis-à-vis study participant interviews, when relevant for the analysis.

3. Study participant characteristics

Of 14 participants, there were: 4 women and 10 men; 4 experts in biology, 4 in epidemiology, 2 in whole genome sequencing, 1 in environmental research, 1 in modelling, 1 clinician, and 1 policy-maker. They were identified at all research levels.

	Total interviews
National	5
Regional	4
Global	5
Total	**14**

The process of inclusion was as follows:

Invited participant area	Unanswered	Accepted & conducted	Total invitations
Côte d'Ivoire	1	3	4
Guinea	6	2	8
Regional	1	4	5
Global	0	5	5
Grand total	**8**	**14**	**22**

Guinea is provided as a good example of timely data sharing during a cholera outbreak, with regards to 2012 response. In 2018, following the country's Ebola experience, cholera seemed to be less of a concern for stakeholders, which resulted in low participation in the study.

4. Responses to study questions

1 To what extent did data sharing occur during the outbreak? What types of data were shared?

Definition of timeliness

Global standards for timely data sharing are impulsed, for instance through UNICEFs shield and sword strategy in West and Central Africa, or with the RSI system. Such systems indicate outbreaks should be reported as soon as they are confirmed with accurate and validated biological testing. This is the starting point for data sharing.

According to IHR (2005), the notification of all cholera cases is not mandatory. The country must declare a cholera outbreak when the isolates' outbreak potential is confirmed (ideally after laboratory confirmation, but in practice when many cases are notified).

Following the confirmation starting point, clinical, biological and epidemiological data must be analysed and shared rapidly, with stakeholders in the response to decide and implement targeted interventions for outbreak control.

Delays in data sharing for declaration and outbreak response

In some instances, countries may delay or not share their data internationally, although their national reporting and collecting systems are operational.

- One factor limiting data sharing during outbreaks is that countries are increasingly (since 2012-2014) confirming the laboratory diagnostic on their own. This technical leadership has been enabled thanks to an increase in skills and available tools for diagnosis at country level. Notably, this is the case for the Institute Pasteur de Côte d'Ivoire, which is also building a regional biobank to support regional expertise on isolates.

  "In Côte d'Ivoire, since maybe 2014, the IPCI has been developing a project for a regional biobank of genetics samples. It is great and completely legitimate! This is the right approach for countries to protect their own resources and be sure that research is done with their country's experts, and officially. Honestly, in the past some specimens were sent abroad without any country approval! It is normal that country experts want to make their work visible. After all, it is a lot of work to collect specimens, product isolates, and manage data. It is as important as the whole genome sequencing!" (International researcher)
- In some occasions, both local and international researchers who contributed to the outbreak confirmation, and then collected, produced or analysed outbreak data (biological and epidemiological data) had difficulty to obtain the country's authorization for publishing the analysed data.
- Other countries in the region may report and share data on 'Acute Watery Diarrhoea (AWD) outbreaks' through the IDSR but refuse to "call it cholera". Other countries in "total black-out" or "cholera denial" will refuse to communicate on any kind of enteric epidemic (cholera or AWD) at all.

  This strategy can backfire with events that become "large outbreaks, because there is a moment when you can no longer hide the issue. It's the curb of country X for instance, it is a paradigm, you can see (draws an epidemic curve starting at several hundred cases on the first week of notification) that there is a large bit of the epidemic that was never described because the ministry did not detect or did not want to notify anyone, they tried to say 'we will manage to control it, we will manage to control it' until the moment when it is clear that you will have to call for external help." (International stakeholder).

Timely declaration of an outbreak and open data sharing

In contrast, international stakeholders describe the attitude of other countries as very transparent about suspected cholera, and very quick to share data on cholera for public health response and research. This was notably the case for Guinea during the 2012 outbreak.

- Openness to data sharing and innovative interventions is often permitted by the presence of a public health 'champion' in affected countries with public health leadership. This implies an acute understanding of the outbreak and potential impact of strategies, a strong sense of public engagement for the most vulnerable, and political leadership to coordinate response stakeholders.
- The long-lasting presence of an NGO, consortium or cluster can accelerate data sharing at early stages of outbreaks. This was notably the case in Guinea through MSF's medical activities and Africhol cholera surveillance program.
- Where technical/laboratorian capacities are not sufficient, international laboratories are solicited to receive and analyse the specimen or isolates. Where countries do not need confirmation from international laboratories, stakeholders are shifting towards quality control, which includes the results of country-based cultures (positive or negative) or evaluation of innovative tools (such as the rapid test during the Guinean outbreak). The provision of training and technology transfer by international laboratories is often a counterpart for dataflows.

2 What were the key barriers to data sharing encountered?

At national level

One main barrier to data sharing is the in-country organisation of cholera surveillance and response, which often results in the unavailability or poor quality of data. The reasons for this barrier are:

- Lack of communication between the clinical, laboratory and surveillance teams, sometimes due to being part of separate ministries.

  "Clinicians are the ones who receive patients and will allow data collection and sharing. But in many countries, hospitals are not working under the authority of the direction for disease prevention and control. That means they don't have any obligation to share information with surveillance stakeholders (both epidemiologist and biologists)." (Regional stakeholders)
- Lack of communication in the field was pointed to by humanitarian stakeholders, who talked about divides between medical and WASH stakeholders at all levels, and how the perception of cholera etiologic (environmental or human) determines decisions for intervention.

  "When you are not a medical NGO, you only have access to the line lists if the medical partner allows this access. You can ask the WASH cluster to facilitate access, but it depends on the medical actors' willingness to share data. In Guinea it was facilitated by MSF." (Regional stakeholder)

  "Even in international institutions you have separate divisions between whole water safety and cholera or enteric diseases. And the guys from one division don't participate in the meetings of the other division. There is a danger. It is like people are protecting their own little areas and their own empires, and not truly trying to get rid of a disease." (Regional stakeholder)
- At national level, stakeholders may refrain from sharing data out of fear they will be "politically" used to undermine the quality of their work (evaluation of national health system performances).

  "There are countless problems to access data […] because people think we come to scold them or report on their shortcomings; they are reluctant." (National researcher)
- Data access may also be tempered by financial requests: "*Once you talk of a 'study', people see the pecuniary interest after all! And some will even tell you 'Oh really? and what's in it for us?'*." (Local researcher)
- No continued surveillance in-between outbreaks.
- During the initial phase (data collection or transfer of materials), technical issues such as the preservation of samples and isolates, or a computer crash for surveillance data, can be a primary impediment to accessing data. Study participants describe the poor field conditions for surveillance and research in developing countries:
  1. Sometimes samples are received directly by private clinics, outside of the surveillance system, with positive results maybe then included in the surveillance system.
  2. A lack of availability and or involvement of technicians due to financial competition between projects and diseases.
  3. No data management at the country level: needs for data management capacities, inadequate tools for timely analysis.
  4. Distance is a hurdle for samples when there is poor funding. Samples from far away must adhere to stricter administrative red tape and may arrive too late to be viable if sent at all.
  5. The need for tools for rapid diagnosis, and conditions of specimen transport, ensuring the viability of the bacteria (avoid false negative results)

Between regional and international stakeholders

The key barrier is a lack of political will

- Disease neglected at international level with little to no funds

  "There are no funds. It is a disease with no market as it doesn't impact high income countries. There is no risk of transmission in Europe or USA. So it is not a priority for funders. Experts are few; researchers in-country prefer to work on more bankable diseases. It is rare to have such a gap between the burden of a disease with about 100,000 deaths per year and 3 million cases, and huge gaps in expertise. It is a neglected disease. It is the disease of the poorest and the most marginalized." (International expert).
- Some country representatives do not declare outbreaks to the international community (WHO) for two reasons: to avoid the potential risk of economic sanctions (i.e. IHR regulation, trade and tourism) and preserve the country's honour (i.e. to be a developing country with improved sanitation conditions). No data means no political reality of disease. *"It's very easy not to have cholera: you don't confirm cholera, you don't have cholera."* (International stakeholder). When country representatives declare a cholera outbreak, it is said to be coming from a neighbouring country.

Between international stakeholders and country authorities or research teams

- Free access to data for interested parties is not frequent. Datasets that follow in-depth analysis are described as 'not understandable' at a country level. Data management tools useful for decision-making are needed. Some teams organize reverting data and analysis, but this does not appear to be standard practice. Some study participants regret the lack of country representatives in international meetings, and country experts denounce a lack of equity: they provide some data, but they do not receive other data from the international team, creating a sentiment of being considered as isolate providers.

Between research teams or even individuals within the same institution: a lack of transparency and fairness

- Legal barriers exist between research teams. The first one concerns missing transfer agreements for some data (surveillance datasets), even if material transfer agreements exist (for isolates). Except for isolates transfers, conditions for scientific partnerships and data sharing seem to be poorly formalized (biosecurity driven formalization), described as a key barrier to data sharing.

  It should be noted that in the reviewed publications (see the concise literature review appendix) there is no clear description of procedures for data sharing. Apart from the reference to IRB approval, there is no information about transfer agreements for data or materials, nor regarding partnership conditions. This lack of transparency or clarification of partnership conditions seems to be the basis for successful interpersonal negotiations, but also leads to misunderstandings and data retention.

  "*According to the Nagoya Protocol, the isolates still belong to the country. And therefore, data sharing is problematic if we don't have the permission. We can do biological confirmation of toxigenic cholera, but we can't publish our results without country approval. And when we ask for this permission, we simply never receive an answer."* (Regional stakeholder).
- Some international researchers noted the Nagoya protocol created confusion about who owned the data, and how data could be shared and publicly published. One understanding is that countries alone are responsible for deciding how and when to share data.

  "Any place we work, we must develop the MTA and DTA, and often, there is very much reluctance to provide materials or data. There was a declaration or something to, I guess, protect the interests of developing countries and ensure they are not taken advantage of, and I think that in some ways, many countries have kind of gone overboard in protecting their interests. Even within countries a ministry may be very protective, even against scientists, their own local scientists. I am in favour of some of these things to be sure that outsiders are not taking advantage, but at the same time it really hurts the local scientists by limiting their access to a higher quality collaboration." (International expert)

Table 2 Synthesis of transparency systems by data type

Data types	Associated studies	Stakes	Do clear national processes exist?	Are there standardized protocols?	Are these applied?	Other processes (case by case)
Stool samples, isolates (strains)	Confirmation by culture or PCR, antimicrobial resistance, phylogenetic studies	Outbreak confirmation, antibiotic treatment, characterization of disease circulation and reservoirs	Heavily framed: Nagoya, IHR 2005, GHSA	Standardized material transfer agreements, other inter-laboratory agreements (such as within the Pasteur Network)	Yes	Projects with specific Master Transfer Agreement to clarify data sharing process, and data uses
Cumulative case reporting	IDSR	Outbreak confirmation and international response	Yes	Yes, IDSR framework, IHR 2005	Delays may occur for index case reporting	Supporting surveillance projects with clear protocols to detail data access and uses
Line lists	Outbreak situation reports, OCV ICG requests, historical epidemiology studies, hotspot modelling, predictive outbreak modelling	Outbreak response; characterization of disease circulation; disease burden	No, except for anonymization of patients	Not always, project by project	n/a	Supporting medical projects with data access; clinical trials with protocols and ethical committee approval
Other numerical or text data	Cost, coverage, vaccine effectiveness, qualitative and KAP studies	Intervention efficiency and cost-effectiveness, adaptability and acceptability	No, except for anonymization of patients	Not always, project by project	n/a	Protocols and ethical committee approval

- Accounts of competition between research teams appear in all interviews and even include competition between researchers within the same institutions. Rivalries concern both access to funds and career-building and result from a perceived lack of fairness between country and international researchers.
  Publishing is a main lever for career-building and success, which requires having access to data. Yet most of our study participants shared experiences of disappointment with regard to receiving scientific recognition from the country and regional experts/researchers, notably in terms of publication and authorship. Some country researchers describe not being associated as an author (being a ghost author), or even acknowledged. International experts have two positions regarding the attribution of authorship:
  1/ Some consider it due to the country partner/ focal point or even technical lead in the partner institution who allows data access. For some study participants, the association of a political representative to a publication (as a guest author with low intellectual contribution) is a means to stimulate a country leader's involvement in the analysis and decision-making for the response.
  2/ Some international experts contend that only authors who make an intellectual contribution to the manuscript must be associated, as stated in the Vancouver protocol. However, they also indicate that the need to build capacity for English scientific writing may be an important barrier towards making an intellectual contribution.
  In our concise literature review (see appendix), analysis of the ranking of authors highlights that African researchers are poorly represented among the two main ranks (last and first authors) but may appear in second or third ranks. In interviews with country stakeholders, this third rank is said to be considered by national committees when evaluating careers of country researchers, because occupying the second,

first or last rank is rare. Field stakeholders (clinicians, surveillance and laboratory technicians) are rarely associated with a publication (except in publications from a country team), or appear in the acknowledgment section, leading to questions about perceptions of country expert roles and status (technicians, service providers versus researcher).

- The retention of data by local partners has been described as a new means of changing the terms of a partnership when they feel exploited. Two positions have been described by study participants: national experts consider they must by generously paid for their contribution/service (some regional and international stakeholders), and others argue they should be fully considered as researchers (part of research and publications) and not only as technicians or isolates providers (national and some international stakeholders).

  "In some countries, researchers want to publish alone without sharing their data because they consider that they were not sufficiently associated with preceding publications. Why not? But if they don't publish, these data will never be shared." (International stakeholders)

  "Some colleagues in countries don't want to share their isolates and data any more. It is their right. They want to be considered as experts. They feel that in the past their work was stolen. I totally agree with them. And I just propose my services if they need my skills in quality control, for instance." (International stakeholder)

- In the meantime, if data access is restricted, it prevents the discussion of results, and leads to the scientific and political supremacy of those able to publish (i.e. theories of reservoir or human-to-human transmission; wash versus vaccine interventions). These divides appear to be institutionalized, with separate meetings and data access conditions to those from a medical or WASH perspective.

Table 3 Weight of responses and respondents' intervention scale distribution: barriers

	International	**Regional**	**National**	**Nb of respondents**	Total occurrences[1]
Barriers					
Rivalries	4	4	1	9	25
Poor relationship quality (no trust and experience of pillaging	4	3	1	6	7
Technical issues	2	2		4	12
Organisation of surveillance in country	2	2		4	9
Neglected disease	1	2	3	6	8
Ownership of country, confidentiality and Nagoya	3	1		4	9
Political retention for economic issues or nation's honour	2	2		4	9
Theoretical divides	2	1		3	5
Centralisation of laboratory confirmation		1	1	2	2
Fear that shared data may be used to undermine the quality of the work performed			1	1	1
No data management	1			1	1
No more funding to support surveillance and laboratory	1		1	2	2
Lack of local personnel availability or involvement		1		1	7
During outbreak is not the moment for partnership discussion		1		1	1

All categories of participants expressed similar sentiments with regards to scientific rivalries and poor mobilisation against a neglected disease. Organisational and technical issues for data collection and data quality are mainly described by regional and international stakeholders.

[1] One respondent may discuss the designated topic several times during an interview

There is no mention about the limitations of data sharing in the published literature we have reviewed. While the incompleteness or unavailability of data is described, there is no information about the potential retention of existing information. This assessment provides a rationale for conducting the present case study based on interviews with research stakeholders.

3 What were the key enablers to data sharing and how did they support the process?

Contributing factors to institutional data sharing agreements

Several modes of opening 'pipelines' of data have been noted:

- "Somebody who knew somebody": interpersonal relationships between laboratories are the main driver of new data sharing collaborations.
- Field presence is critical to obtain on time and ongoing datasets: this includes but is not limited to situations of chronic crises with a heavy and long-lasting NGO presence and strong clusters that allow ongoing data sharing.
- Decentralizing laboratories is key to deploying surveillance.
- Institutional multipass: The 2014 reactivated GTFCC (WHO secretariat) has provided an excellent tool to access to key ministerial officers in any given country. The rationale is that the institutional GTFCC member with the closest ministerial ties can serve as a bridge for other partners. This tool depends on the internal establishment of a common research agenda.
- Funders requesting a multi-expertise approach and consortium (i.e. North-South)
- Sharing data may allow international organisations to consider a country's specific needs.

Operational value of knowledge

Lack of local know-how: one driver towards data sharing is that the country "understands" its technical knowledge deficit and perceives that international actors have operational value. In this process the use of technological transfer and local staff training is a great enabler, as it can reduce the knowledge gap while providing up-to-date knowledge about the deemed operational value. The availability of data management tools, with guarantees of historic data protection and data summaries for decision-making (for instance, fact sheets about epidemiology and hotspots) is welcomed. Many participants stated that cholera is not a difficult pathogen to manage (unlike Ebola & other haemorrhagic fevers).

Personal enablers of data sharing

- Scientific consideration in general, and provision of authorship more specifically, were key personal motivators for collaboration and data sharing.
- The personal investment of public health champions (country leader), as in Guinea during the 2012 outbreak, is also cited as a key individual driver of data sharing.
- More generally shared work ethic among public health workers, influenced either by political views (i.e. working for the disadvantaged), religious values or a military ethos can also motivate people to research data sharing for public health.
- Local staff is trained to meet international regulations of material and data sharing.
- Lastly, the provision of international invitations or even gifts is also cited as a personal stimulator, albeit participants tend to view this practice unfavourably.

Rules of transfer

- For most participants, the terms of data sharing transfers should: be based on interpersonal relations, be established on a case by case scenario, and rely on trust.
- Others, however, would prefer more standardised approaches.

1. A first, formalising branch would seek to protect the country's rights with regards to the strains.
2. A secondary branch would grant legalised access for international actors to country data, through a standardised system with transparent terms of data sharing and protocol for data collection and access.

Table 4 Weight of responses and respondents' intervention scale distribution: enablers

	International	Regional	National	Nb of respondents	Total occurrences
Personal enablers of data sharing					
Providing authorship	3	1	4	**8**	10
Public health champions	2	3		**5**	12
Work ethic / sense of duty		2		**2**	5
Gifts		1	1	**2**	3
Scientific consideration			1	**1**	2
Similar moral or ideological position		1		**1**	1
Operational value of knowledge					
Technological and knowledge transfer	2	3	1	**6**	10
Operational value of international partners	1	1		**2**	3
Understanding of personal knowledge deficit	1	1		**2**	3
Lack of local know-how	2			**2**	2
Offering data management and tools for decision-making	2			**2**	2
Contributing factors to data agreement					
Field presence		2		**2**	8
Existing institutional agreement	1		1	**2**	4
"Somebody who knew somebody"	1	1		**2**	2
Institutional multipass-GTFCC	1	1		**2**	2
Coordinated funding		1		**1**	2
An international research agenda	1			**1**	2
Highlighting the country's needs at an international level			1	**1**	1
Chronic crises with heavy NGO presence	1			**1**	1
Rules of transfer					
Inter-personal or loose agreements	1	2	2	**5**	6
Formalising from the North - granting access		1		**1**	1
Formalising from the South - protecting countries	1			**1**	1
Technical innovations		1		**1**	1
Committees for partnership		1		**1**	1

Three main enablers for data sharing shared by all categories of participants suggest a clear strategy: provide authorship, and transfer technological capacities and knowledge, based on interpersonal agreement.

4 How could greater availability of data have enhanced the response?

All study participants described that greater availability of data could have enhanced the response.

- A greater availability of clinical data is needed, including indications about patients (specifically localisation) that are mostly produced in cholera treatment centres, in addition to epidemiological data. This would allow field epidemiology analysis and the design of response intervention strategies that target hotspots cost-effectively.

  "Line lists from cholera treatment centres, including patients' localities, should be shared with all partners to better identify hotspots and allow targeted intervention." (Regional stakeholder)

- Biological work on isolates (cultures, PCR, DNA and antibiograms) allows for the identification of the cholerae strains. This defines the outbreak potential of the vibrio cholerae strain, and the possible best treatment strategy (at least for severe cases). During or after the outbreak, antimicrobial resistance (AMR) testing with the existing available isolates enables identification of the *V. cholerae* antimicrobial pattern. This can define the best care/treatment strategies for coming outbreaks. There is currently no consensus on the use of antibiotics, despite the existing WHO protocol. Some current studies evaluate the impact of antimicrobial treatments on patient contacts to reduce the disease burden. Others meanwhile argue for a more global health approach that considers the risk of an increased anti-microbial resistance to other pathogens and insist on the importance of WASH strategies instead of antibiotic use.

  "For me, research on anti-microbial resistance is a priority. WHO recommends to reserve antibiotics for severe cases and pregnant women. Research explores other possibilities. For instance, if you positively test a patient with cholera, using a rapid test, you could consider giving antibiotics to stop the symptoms. This would reduce the disease burden and limit the cholera transmission. Some teams consider giving antibiotics to household members for prevention. This is possible if anti-microbial resistance is reversible." (International stakeholder)

  "You are going to create resistance to other pathogens as well. I think it's far better to rely on good health education than always on some sort of magic bullet." (Regional stakeholder)

- In general, research stakeholders all argue for data to be more widely available to build a more holistic approach beyond the divides of expertise (clinical, epidemiological or biological), theoretical empires (environmental reservoir versus human-to-human transmission), intervention sector (medical versus WASH) and position (country versus international). This is both for critical scientific discussions (to avoid bias of selection and publication), and to provide accurate and timely information for countries to design an integrated approach to their response.

  "For any enteric disease, and for any of the zoonoses such as Ebola, if you are not considering it from all aspects, it is not going to work. I don't think cholera is eradicable, because the organism can survive so well in the environment. The best we can really look for is control, and control has to be multi-pronged." (Regional stakeholder)

  "There is an important bias of publication. Even now, researchers are still searching for vibrio cholerae in the environment and if they don't find it, they conclude that they didn't search with the right method. These data should be published and shared to contribute to the general knowledge about cholera." (International stakeholder)

- Some research stakeholders are planning to design online data management tools. These may allow timely open source access with understandable analysis of data (i.e. for the DNA identification of isolates at a country level in order to define the risk of outbreak, or for the simulation of spread based on surveillance data to anticipate the routes of spread and at-risk countries).

  "The next steps in terms of research and country response are to develop tools for biological analyses based on the findings from the whole genome sequencing. We should share the characterisation of short sequencing with the country, for the rapid identification at a country-level using PCR." (International expert)

  "We are developing dashboards to more easily get data from the CTC (line lists), provide rapid standard analysis and clear visualisation of epidemiological data, and predict the possible

impact of reactive vaccine campaigns on the disease burden. It allows timely data sharing with all levels and can help countries to rapidly reach a decision about their response strategy." (Regional stakeholder)

- The availability of data is also important to provide evidence to international financial partners about cholera control. For instance, evaluations of vaccine effectiveness, feasibility, acceptability and safety were described as being designed and used to advocate for vaccine development and international financial support for reactive and preventive campaigns. Other teams work on different intervention strategies (WASH) to demonstrate the impact each activity has on cholera control, as well as the most cost-effective strategies to be decided and funded.

  "MSF supported the first reactive OCV campaigns in Guinea in 2012 and in South Sudan in 2013. There was no funding for OCV vaccines and WHO was not convinced by the vaccine impact on disease burden. We evaluate the campaigns to provide evidence and respond to all targeted issues: about the feasibility and acceptability of the vaccine as well on vaccine effectiveness." (Regional stakeholder)

5 Which lessons learned about enablers for data sharing are generalisable?

- The country-driven approach became the main framework for research and response in the context of an emergency. Since 2012-2014, it became clear that country authorities and national institutes for disease surveillance and control are willing to produce and manage data on their own, and with the commitment of their country experts. Where countries already have expertise, research partnerships with international research teams should propose technical solutions or capacity-building or the evaluation of innovative tools that may help to control outbreaks. In summary, countries are becoming clients, and are no longer specimen providers, while international researchers and partners increasingly become service providers.
- Agreements for research partnerships and materials, or data transfer agreements, are increasing in their transparency (about role distribution) and fairness (in authorship), thereby improving the scientific recognition of all counter-parts. Prior to signing an agreement, inter-personal trust is built through face-to-face interactions and the in-field presence of international researchers. Agreements must be signed between outbreaks to allow for timely data sharing, impact assessment interventions, and outbreak detection.
- Year-round (as opposed to 'outbreak-specific') financial support of the national surveillance system is a key condition for data availability, and therefore data sharing.
- For cases in which some countries retain information for political purposes, which creates significant bottlenecks during health emergencies, there exists an informal system of alerts or data sharing via short, direct contact, or the local NGO presence. Delays between the confirmation of the index case and declaration of the epidemic can be huge, limiting the possibilities for outbreak control and leading to higher disease burden. However, communicating data (isolates or analytical data) about suspected or confirmed outbreaks in a way that bypasses country authorities, and in parallel to formal partnerships, can be very risky for clinical/biological/surveillance stakeholders. One interview described a case in which a whistle-blower was imprisoned. There is no consensus among study participants on the duties of a clinical/biological/surveillance stakeholder when faced with a possible cholera outbreak. At a country level, the person responsible for relaying information to the Ministry of Health is clearly identified, and staff must not communicate on their behalf. When biological confirmation is made outside of the country, the biologists refer to their client, who is both the country provider and the institution that has paid for the results. Thereafter, they play no role in making the data available. One study participant suggested that all professionals, from clinical to international research teams, have a duty to alert, or even confirm to, the regional authority. This would ensure at-risk neighbouring countries have timely information for deploying preventive strategies and open data access. Advocating against import bans for goods coming from cholera-declared countries could significantly decrease the economic cost of notifying about cholera.

6 Who is responsible for implementing proposed changes (e.g. research community or funders) based on lessons learned?

Several stakeholders have responsibility for implementing changes, from the individual researcher in a country, to international funders.

- The individual researchers in the country must take part in discussions regarding the use of data they have compiled, not least to provide visibility about their potential ownership/authorship. The study protocol must include the distribution of roles and duties and be clear for all stakeholders involved. The participation of local researchers (and funding of this participation) in designing the studies and crafting the protocol, is key to ensure the products of the study will be shared equitably at later stages of the research.
- The researchers' teams/institutions must undertake similar negotiations to ensure transparency over the legal conditions for collecting and sharing (including publishing) data.
- Supra experts at the international level must be responsible for sharing data regardless of competition (for funds, expertise, theoretical empires etc.) and revert information to their country counter-parts.
- Countries, and clearly identified focal points, are responsible for inter-country legal partnerships for research and data ownership.
- Regional institutions and funders must lead the development of regional initiatives for data sharing, both for collection and preservation of samples and isolates (biobank) and archives of associated data, and for outbreak surveillance/alert/confirmation to prevent cholera spread.
- International stakeholders (including decision-makers, public health stakeholders and funders) such as WHO (GTFCC), CDC, OAS, BMGF must be involved to positively evaluate and support country leadership and data-sharing initiatives. The BMGF and UNICEF were cited for their support for holistic/integrated approaches that bridged the divides of expertise, theories, intervention domain and regions. The concise review of literature (see appendix) shows how UN funds and BMGF appear to result in cross-regional partnerships, the sharing of authorship (including country representatives), and more transparency about data collection and data sharing processes.

5. Table 5 Synthesis of PEARLES barriers, enablers and recommended solutions

Type of barrier	Detail	Existing enablers	Recommendations from participants	Recommendations from team
Political	Political retention of outbreak notification and cholera data to protect national economy and pride.	Public health champion/ country leadership; counter-part (WHO); informal notification system for international surveillance.	Advocate towards countries that declare import bans on cholera-reporting countries. Advocate for timely outbreak declarations; sovereignty-related barriers (vs regional public health) could be leveraged via regional organisation such as the West African Health Organization (WAHO).	Conduct a qualitative assessment to understand political retention and acceptable enablers from a country's perspective. Initiate legal protection of technicians and clarification of duties regarding declaration.
Ethical	Poor relationship to quality (no trust, and experience of pillaging).	Gift of capacity-building or career-building or wages; scientific consideration including granting of authorship; same sense of duty; same moral values.	Build capacity; discuss authorship at the early stages of collaboration.	Develop international guidelines for writing up clear protocols that address data ownership, usufruct and authorship; technical capacity-building. Provide capacity-building for manuscript writing.
Administrative	Centralisation of laboratory confirmation; organisation of surveillance in country. Fear that shared data will be used to undermine one's work and career (i.e. case fatality ratios).	Need of field presence for data sharing; clear protocols; disseminating research results.	Provide tools for local confirmation; open data management; timely alerts; need to foster a research-oriented mindset among clinicians.	Provide with technical and financial support. Initiate discussion on the legal protection of surveillance/ laboratory technicians, regional alert systems. Provide feedback to clinical centres with research results to better explain data usage and add value to disease understanding and control.
Regulatory	Countries have ownership of data, confidentiality and Nagoya.	Direct personal contact for data sharing; international agenda; existing institutional agreements.	Either use standardised, precise and binding protocols; or formalise on a case-by-case basis and rely on trust.	Clarify international guidelines about data sharing. Develop a toolkit about Nagoya protocol and data ownership.
Logistical	No data management; lack of local personnel in terms of availability or involvement; outbreak is not the moment for partnership discussions.	Offer data management and tools for decision-making; technological and knowledge transfer.	Need for capacity-building and financial support.	Open source and consortiums with rules for authorships should be leveraged by funders and peer-reviewed journals.
Economic	Cessation of funding to support surveillance and laboratory.	Coordinated funding	Surveillance funding should continue in-between outbreaks; funding contracts should enable better dissemination of results by peer-reviewed journals or public repositories to increase cross-fertilisation and avoid publication biases (including of negative results).	
Social	Rivalries; lack of sense of duty towards vulnerable populations.	Clear protocols on data sharing and authorship; involvement of a public health champion devoted to their population (even the marginalised or poor).	Preference for open data access; identify devoted focal point/ public health champion.	Preference for pre-publication data publishing repositories. Consider local moralities and sense of duty during advocacy for data sharing.

6. Suggested next steps for conclusion

Political and regulatory leverage

- The perception of what it means to have cholera (in one's country) is a major barrier for cholera data sharing. The more developed a country with cholera, the more likely that its surveillance data and laboratory confirmation will be independent, and therefore the higher the symbolic cost of admitting to having the disease.
- When political retention of data exists there is usually an informal alert system in place. The question is how to formalise this and offer legal protections for national and regional public health technicians/researchers, and protection of data (bio-protection for biological data, protection of individuals when data is personal).
- The Nagoya protocol must be explained to countries and research stakeholders, and specifically the questions regarding who owns the data; what can be done with data already shared by country representatives; and the duty to share data (open access to data sets, or publication of results).
- A solution might be to identify an a-political, independent committee, such as the ethical committee, to ensure timely alerts, data quality, respect for safety conditions of data sharing, and respect for study protocols regarding the fairness and equity of data sharing. Such institutions may be regional, in order to overcome the country's decision-making and prevent cross-country spread (i.e. AFRO/WAHO or African Union etc.).
- It might be helpful that the WHO/GTFCC provides standard guidance/protocols about data sharing during and in-between outbreaks, including safety conditions and partnerships prerequisites.
- There is a need for advocacy for early warnings during onsets of cholera outbreaks. Rapid qualitative assessment should be conducted to identify barriers from the perspective of interested countries and should identify key messages to be communicated to change their positions and early response.

Economic and technical/logistical barriers

- There is consensus on the need for financial and technical support to improve the quality of data at the field level as a first step towards data sharing. There is a need for innovative tools, such as local biological analysis (confirmation and identification of strains to confirm outbreak potential), and for clinical/epidemiological data management tools to revert data back to the country and allow timely decision-making for outbreak response.
- Sustainable (non-emergency related) financial support is required to allow continued cholera surveillance in-between outbreaks.

Ethical and social leverage

- Restriction of access to data is often due to competition and division of funds, or institutional or scientific honour. Promoting open access, consortiums and cross-fertilisation must be enhanced to avoid duplicate studies (and competition for giving access to data with risks of choice for the highest bidder). One tool for early data sharing can be pre-publication open repositories of datasets or reports (i.e. BMGF initiative).
- Public health stakeholders (WHO-UNICEF), funders (BMGF, UN and governments) and peer-reviewed journals should act as regulators to improve cross-fertilisation, transparency, fairness and equity, timeliness and the quality of research and partnerships.
- With regard to the fairness of scientific recognition, the following types of leverages are suggested to be addressed in international protocol/consensus:
    1. How and when does a contributor become a researcher who deserves to be acknowledged as an author (i.e. for a technical role or Intellectual contribution, as a political facilitator or member of research team, or for access to data).

2. There is a need to build capacity for local teams to improve how they write scientific papers, and how they make in-depth analyses to ensure all conditions for authorship align with international standards. Publication language barriers must also be addressed.
3. It might be a useful prerequisite to build partnerships that plan for co-first/last authors in Africa and Europe/America, with strong support from funders (example of BMGF and UNICEF) and peer-reviewed journals.
4. Research protocols must clarify the distribution of roles (because of language and technical gaps) and clarify who will receive invitations to attend meetings or conferences in the dissemination phase. To ensure country teams are represented, an international fund may be created and financed by each research study related to cholera.

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