RESPONSIBLE DATA FOR CHILDREN

CAI (CELLULE D'ANALYSE INTÉGRÉE) CASE STUDY: USING DATA-DRIVEN METHODS TO RESPOND TO COMPLEX DISEASE OUTBREAKS

GOVLAB unicef 🧐

This case study is part of the Responsible Data for Children initiative, an effort to build awareness regarding the need for special attention to data issues affecting children. This case study aims to offer insights on promising practices as well as potential barriers to realizing responsible data for children through the experience of Cellule d'Analyse Intégrée (CAI). The material relies on interviews, internal documents, and public information



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I. ABSTRACT

Cellule d'Analyse Intégrée (also known as the Integrated Analytics Cell or CAI)¹ is an operational research and analytics cell created by UNICEF to provide local and national level actors (health, civil society), government leaders, United Nations (UN) staff, and associated partners with integrated and actionable evidence to respond to public health emergencies and contexts. It came about to support the response to the tenth Ebola outbreak in the eastern part of the Democratic Republic of the Congo (DRC). Relying on an analytical approach known as "Integrated Outbreak Analytics" (IOA), the CAI has both local teams who collect data in communities through mixed methods and a team of national and international researchers who support study designs, data collection and analysis and who produce insights on this data that can be used for public health decision-making at multiple levels. Based on its role in helping the DRC government bring an end to the tenth Ebola outbreak, the initiative has expanded to support different public health concerns across the country, including cholera, polio, measles, malnutrition and gender-based violence. The CAI has also provided support to different countries including Guinea (Ebola outbreak in 2021); the Republic of Congo (COVID-19) and Ghana (Marburg outbreak 2022). The CAI's experiences demonstrate the RD4C principles of purpose-driven (the CAI team's research has led to more tailored policy and communication responses), participatory (the CAI team includes stakeholders with a wide variety of expertise and perspectives), and proportional (the CAI team only collects data when we can be sure it will be used and usable).

Tags: Purpose-driven; Proportional; Participatory

¹ CAI's name has changed several times over the course of its lifetime. For the sake of clarity, it is referred to as CAI when referred to generally and by its historical names when referring to a particular span of time.

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II. THE ISSUE AT HAND

The Democratic Republic of Congo (DRC) suffers regular outbreaks of polio, cholera, measles, and plague. In August 2018, the Congolese Ministry of Health (MoH) declared an outbreak of Ebola Virus Disease (EVD).² Unlike previous outbreaks in other regions, humanitarian and security challenges stemming from the Kivu conflict hindered timely response efforts and prevented health officials from identifying and contacting those infected.³ The disease saw rapid expansion-with new cases doubling from 1,000 in March 2019 to 2,000 in June 2019. It subsequently became the world's second-largest Ebola outbreak⁴ with 3,470 cases reported and 2,287 deaths (a fatality ratio of 66%).5



FIGURE 1: Map of areas affected by the outbreak.6

This situation presented an enormous challenge for local, national, and international public health authorities. In addition to the ongoing conflict situation in the areas affected, the DRC suffered from low state and health system capacity,⁷ hostility toward UN and government personnel stemming from failures in the past to address the sources of insecurity as well as a variety

² World Health Organization. "Ebola Virus Disease – Democratic Republic of the Congo." WHO, August 4, 2018. <u>https://www.who.int/emergencies/disease-outbreak-news/item/4-august-2018-ebola-drc-en</u>.

³ World Health Organization. "Ebola Outbreak 2018-2020- North Kivu-Ituri." WHO, December 16, 2021. <u>https://www.who.int/emergencies/situations/Ebola-2019-drc-</u>.

⁴ U.S. Centres for Disease Control. "History of Ebola Virus Disease (EVD) Outbreaks | History | Ebola (Ebola Virus Disease) | CDC." CDC, February 18, 2022. <u>https://www.cdc.gov/vhf/ebola/history/chronology.html</u>.

⁵ Guetiya Wadoum, Raoul Emeric, Stephen Sevalie, Antonella Minutolo, Andrew Clarke, Gianluca Russo, Vittorio Colizzi, Maurizio Mattei, and Carla Montesano. "The 2018–2020 Ebola Outbreak in the Democratic Republic of Congo: A Better Response Had Been Achieved Through Inter-State Coordination in Africa." Risk Management and Healthcare Policy 14 (December 10, 2021): 4923–30. <u>https://doi.org/10.2147/RMHP.S327616</u>.

⁶ "Rapport Annuel 2021." Democratic Republic of Congo: Cellule d'analyse intégrée, 2021. <u>https://www.unicef.org/</u> <u>drcongo/media/7781/file/COD-CAI-rapport-annuel-2021.pdf</u>.

 ⁷ "Balan, Pablo, Augustin Bergeron, Gabriel Tourek, and Jonathan Weigel. "Can Low-Capacity Governments Work with Local Leaders to Increase Tax Revenues? Evidence from the Democratic Republic of Congo," October 19, 2020. <u>https://voxdev.org/topic/public-economics/can-low-capacity-governments-work-local-leaders-increase-tax-revenues-evidence-democratic-republic-congo</u>.



Figure 2: An example of data sources that could be used to achieve IOA.8

of infrastructural limitations that made travel difficult or dangerous.⁹ Consequently, UN personnel and partners realized health authorities would need a coordinated response that could grapple with the size, complexity, and shifting nature of the outbreak. To achieve this response, government officials needed data from various, diverse sources to inform decisionmaking on the Ebola response.¹⁰

The Government of the DRC and UN personnel found their answer in Integrated Outbreak Analytics (IOA)—a multidisciplinary approach to outbreak

dynamics that aims to "understand and describe epidemiological findings through the social, environmental, and behavioral drivers and barriers that influence outbreak dynamics and the impacts of outbreaks on communities."11 Instead of being a standardized methodology in which epidemiologists focus on who is affected by a disease, when it is occurring and how quickly it is spreading, where it is spreading, and what is the pathogen, IOA looks at the larger picture.¹² It seeks to understand why certain groups are more susceptible than others and how certain families and communities may respond to the public

⁸ Rohan, Hana, and Gillian McKay. "The Ebola Outbreak in the Democratic Republic of the Congo: Why There Is No 'Silver Bullet." Nature Immunology 21, no. 6 (June 2020): 591–94. https://doi.org/10.1038/s41590-020-0675-8
⁹ Ibid.

¹⁰ Carter, Simone E., Steve Ahuka-Mundeke, Jérôme Pfaffmann Zambruni, Carlos Navarro Colorado, Esther van Kleef, Pascale Lissouba, Sophie Meakin, et al. "How to Improve Outbreak Response: A Case Study of Integrated Outbreak Analytics from Ebola in Eastern Democratic Republic of the Congo." BMJ Global Health 6, no. 8 (August 1, 2021): e006736. <u>https://doi.org/10.1136/bmjgh-2021-006736</u>.

 ¹¹ Rohan, Hana, and Gillian McKay. "The Ebola Outbreak in the Democratic Republic of the Congo: Why There Is No 'Silver Bullet.'" Nature Immunology 21, no. 6 (June 2020): 591–94. <u>https://doi.org/10.1038/s41590-020-0675-8</u>.
 ¹² Integrated Outbreak Analytics (IOA) GOARN. What Is Integrated Outbreak Analytics (or IOA)? (ENG), 2022. <u>https://www.youtube.com/watch?v=ZC0hZr2YVpM.</u>)

To achieve this goal, IOA incorporates a variety of datasets. It uses surveys, interviews, and focus group discussions as well as data from health facilities, health program reports, and major events to reveal the role of different elements in facilitating disease spread (see Figure 1).¹⁴ By necessity, this approach is always performed at the local level to accommodate the specific context. It relies on partnerships to gather data and co-develop evidencebased recommendations.¹⁵ It can provide insights on "health services, perceptions and behaviors of the communities (people), staff of health and care (availability, risk, changes), events and chronology (policies, restriction, information, response strategies), markets, prices and the context (possible conflicts, gender dynamics, culture."16

Prior to the 2018–2020 outbreak, there had been no formal set up of an IOA team in the field during a public health emergency. It also had not integrated data to include critical information from programmes, from health information systems, from context (displacement, seasonality, poverty) and from social and behavioral sciences. However, UNICEF saw an urgent need to support the MoH and partners to control EVD's outbreak. The DRC MoH, supported by an international group of partners including UNICEF. International Federation of the Red Cross, World Health Organization (WHO), the Centres for Disease Control-Atlanta, Médecins Sans Frontières— Epicentre, the International Rescue Committee, and Oxfam began exploring ways to integrate it into the national disease response.¹⁷ The diversity of these actors reflects IOA's own multiactor and multi-disciplinary approach to disease outbreaks.¹⁸

III. ACTION

ORIGINS

This collective response emerged in September 2018. UNICEF, World Health Organization, the US Centers for Disease Control, Médecins Sans Frontières-Epicentre, International Federation of Red Cross and Red

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Carter, Simone. "Integrated Outbreak Analytics (IOA): Terms of Reference v1.0," November 20, 2021. <u>https://drive.google.com/file/d/1FRnw7jfWSkT2frt5J9JKDuxHKI3VGr3F/view.</u>

¹⁶ UNICEF CASS. "2020-04-11_CASS Guide Pour Une Nouvelle CASS (Lecons Ebola RDC) FR." April 11, 2020. <u>https://docs.google.com/presentation/d/1tr4dZ1tmrXmeRciH6cxfill52ZNBSLzt</u>.

¹⁷ Carter *supra* note 16.

¹⁸ Integrated Outbreak Analytics (IOA) GOARN. How IOA Is a Multi-Actor and Multi-Discipline Approach? (ENG), 2022. <u>https://www.youtube.com/watch?v=31tla7X7Zyk</u>.

Crescent Societies, and other locally and internationally relevant nongovernmental organizations came together to use IOA methods to understand specific trends in the outbreak.¹⁹ Participants were interested in, for example, if there was a higher EVD caseload for children under the age of five than other cohorts.²⁰

The structure through which this collaboration developed over time in an iterative, organic fashion began with immediate response to needs in the field (see Table 1 for overview). Initially, the partner organizations came together to create a service within the preexisting Ebola response structure.²¹ Operations centered on recruiting a social epidemiologist working together with all actors, including local and international NGOs, on data collection, analysis and use. As early as October 2018, IRC and Oxfam were supporting the IOA approach through local staff made available to support on data collection. Further partnerships took place in November 2018 when Medair, an EVD healthcare provider, requested support in identifying challenges regarding gaps between EVD cases and

alerts raised within their facilities.²² In February 2019, the collaborators hired their first team of full-time local researchers, who worked out of Butembo in North Kivu.²³

¹⁹ Carter, Simone E, Steve Ahuka-Mundeke, Jérôme Pfaffmann Zambruni, Carlos Navarro Colorado, Esther van Kleef, Pascale Lissouba, and Sophie Meakin et al. 2021. "How To Improve Outbreak Response: A Case Study Of Integrated Outbreak Analytics From Ebola In Eastern Democratic Republic Of The Congo". BMJ Global Health 6 (8): e006736. doi:10.1136/bmjgh-2021-006736.

²⁰ Ibid.

²¹ Ibid

²² Ibid

²³ 10 of the parties operated under the umbrella of UNICEF and the other 10 under the World Health Organization. See: Cellule d'analyse en sciences sociales. "2020-04 BRIEF CASS Ebola RDC (FR) VF.Docx." Google Docs, April 2020. https://docs.google.com/document/u/3/d/1h5v7qM6Vr4wApUM0KIQXyEQZSn2Tw5IT/.

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Table 1: CAI's Emerging Response to EVD in DRC 25	
Date	Description
September 2018	UNICEF recruits a social epidemiologist to support understanding of outbreak dynamics related to the EVD outbreak.
October 2018	UNICEF begins its first operational studies in the field.
February 2019	First team of local researchers (10 hired by UNICEF and 10 by WHO) formed in Butembo in North Kivu.
March 2019	UNICEF and partners draft terms of reference with the government of the Democratic Republic of Congo to form a unit dedicated to social science research. The unit is integrated into DRC's overall response to EVD and takes the name Cellule d'Analyse en Sciences Sociales (CASS).
July 2019	MoH, UNICEF and partners organizes brainstorming workshops with the sub-coordinations, with the sub-commissions overseeing the national response to EVD to improve coordination. The workshop leads to the development of an Excel-facilitated tool called "MONITO," which can be used to co-develop recommendations.
January 2020	The CASS team hosts a mission from Global Outbreak Alert and Response Network Research, a network of public health institutions. The mission visit is funded by Wellcome Trust and the United Kingdom's Foreign, Commonwealth and Development Office, who seek to model CASS and document lessons they can apply to future crises.
February 2020	CASS develops new terms of reference with the DRC's Strategic Coordination and Technical Secretariat. The parties modify the process for developing recommendations to further encourage co-development, ownership, and collaboration among partners.
March 2020	The 10th EVD outbreak comes to an end. The MoH, UNICEF and partners recognise the critical role of replicating this approach within the COVID-19 response. UNICEF sets up a formal unit within the country office and the MoH includes the Integrated Cell within the COVID-19 response plan. As the CASS brings together the IOA approach and multiple data methods; the name is changed to the Cellule d'Analyse Intégrée/Integrated Analytics Cell (CAI).
June 2020	Publication of lessons learned for COVID from CAI's experiences responding to Ebola. Cell is replicated in the Equateur province to respond to the government's declaration of the 11th EVD outbreak.

²⁴ Carter, Simone. "The Social Sciences Analytics Cell (CASS), the Epi Cell & IOA: DRC & Global." UNICEF, July 2021.

However, as collaborations expanded and deepened over the following months, the collaborators found it necessary to better define what their work entailed and the responsibilities of different actors involved. In March 2019. UNICEF drafted a terms of reference with the DRC Ministry of Health. These terms of reference formed a unit dedicated to social science research within the overall EVD response. The CASS worked side by side with the Epidemiological Cell, and together they produced IOA. Between June and July 2019, amid the development of the fourth iteration of the government's Strategic Response Plan, this unit took the name of Cellule d'Analyse en Sciences Sociales (CASS).²⁵ It also held a series of workshops with officials representing different regional Ebola response coordination hubs to find ways to improve coordination and data collection and analysis.²⁶ The result was the development of a new tool for tracking social science research recommendations called MONITO (described below).27

Over the following months, CASS met with partners and developed revised terms of reference with DRC's Technical Secretariat (the body placed in charge of EVD response).²⁸ Through this process (following the tenth EVD outbreak), CASS, integrating the Epidemiological Cell work, evolved into the Cellule d'Analyse Integree (CAI). Similar to how it had before, CAI works to "provide a better understanding of outbreak dynamics to support evidence-based decision making during public health emergencies" by conducting rapid studies; providing real-time insights to policymakers on oubtreaks; bringing together data sources; and training researchers and developing national partnerships to strengthen the use of IOA methods. ²⁹

Since the MoH declared an end to the tenth EVD outbreak in March 2020, CAI has become a formal unit within UNICEF's country office (and is replicating the set-up within the DRC MoH) that responds to different health emergencies as they occur. CAI has

²⁷ Cellule d'analyse en sciences sociales. "Recommandations Issues de l'étude Reconstruire La Confiance Des Communautés Affectées Dans Le Personnel de Santé." Democratic Republic of Congo, April 1, 2020. <u>https://docs.google.com/document/d/1hsohg4y5KOodl9myDzC7Qu6MdavQTLia/edit?</u> usp=drive_web&ouid=113081253733150357432&rtpof=true.

²⁵ It is known as the Social Science Analytics Cell or CASS in English.

²⁶ For information on the response structure, see: McKay, Gillian, Ombretta Baggio, Cheick Abdoulaye Camara, Eva Erlach, Lucia Robles Dios, Francesco Checchi, and Hana Rohan. 2022. "'The Response Is Like A Big Ship': Community Feedback As A Case Study Of Evidence Uptake And Use In The 2018–2020 Ebola Epidemic In The Democratic Republic Of The Congo". <u>https://gh.bmj.com/content/7/2/e005971.abstract</u>.

²⁸ Carter, Simone. "2020-02 TdR Cellule d-Analyse En Sciences Sociales (CASS) Version Finale.Pdf." Cellule d'Anlayse en Science Sociale, February 5, 2020. <u>https://drive.google.com/file/d/</u> <u>1S5abkuYnQ4lyDI3z5dB0qyMDBujzWkT_/view?usp=sharing</u>.

²⁹ UNICEF. 2022. "Integrated Analytics Cell (CAI)". *Unicef.org*. <u>https://www.unicef.org/drcongo/en/integrated-analytics-cell</u>.

worked on COVID-19, cholera, plague, malnutrition, measles and four more EVD outbreaks in the DRC. It has also provided support to other countries in the West and Central Africa Regional Office of UNICEF,³⁰ and, in 2022, has started supporting Haiti's MoH to set up a CAI within their ministry of health.³¹

DEPLOYMENT

The CAI deployment begins with an alert of a new health emergency or increasing concern regarding an existing public health context; this could be an EVD alert or a peak in measles cases in a particular location. After national authorities decide there is a health need and that CAI can provide value, the CAI team develop terms of reference with appropriate national leaders. In the context of the DRC, officials included the Congolese Minister of Health and community and NGO partners involved in disease response. These terms of reference outline responsibilities and how CAI best provide operational analytics in order to provide near-realtime data to inform decision-making in outbreak or public health response given the resources available.

Completing these terms of reference involves first identifying key questions with local actors (progress on which may be reviewed daily, weekly, or monthly depending on the intensity of the outbreak), the information needs (the objectives), the methodology that will be used, and how results collected will be used.³² The terms grant the partners ownership over process and can influence the development of the recommendations.³³ Consistent with IOA best practices, if CAI cannot identify how the results will be used or by whom, it will not conduct the study.³⁴

In the response effort to EVD from 2018-2020, the CASS terms of reference included a six-person core team led by a member of the ministry of public health and UNICEF staff who served a variety of roles involving epidemiology, field research, humanitarian assistance, and data analytics.³⁵ The core objectives, as

³⁰ UNICEF. 2020. "West And Central Africa Coronavirus (COVID-19) Situation Report No. 4". UNICEF. <u>https://www.unicef.org/media/79846/file/WCARO-COVID-19-SitRep-15-June-2020.pdf</u>.

³¹ Integrated Outbreak Analytics (IOA) & Early Warning of Public Health Emergencies (IOA WorkingGroup), 2022. <u>https://www.youtube.com/watch?v=jxxZg_9XOkk</u>.

³² Integrated Outbreak Analytics (IOA) & Early Warning of Public Health Emergencies (IOA WorkingGroup), 2022. <u>https://www.youtube.com/watch?v=jxxZg_9XOkk</u>.

³³ Carter, S., Ahuka-Mundeke, S., Pfaffmann Zambruni, J., Navarro Colorado, C., van Kleef, E., Lissouba, P., Meakin, S., le Polain de Waroux, O., Jombart, T., Mossoko, M., Bulemfu Nkakirande, D., Esmail, M., Earle-Richardson, G., Degail, M., Umutoni, C., Anoko, J. and Gobat, N., 2021. How to improve outbreak response: a case study of integrated outbreak analytics from Ebola in Eastern Democratic Republic of the Congo. *BMJ Global Health*, 6(8), p.e006736.

³⁴ Integrated Outbreak Analytics (IOA) GOARN, *supra* note 34.

³⁵ Cellule d'analyse en sciences sociales. "Membres Equipe CASS Ebola RDC." Google Docs. Accessed August 23, 2022. <u>https://docs.google.com/spreadsheets/u/3/d/1e69lp9eEudu9UIW7XXBs4gXXQL5lu_dwGRg7rhdCKac/edit</u>.

stated in the March 2019 terms of reference, were supporting the EVD outbreak response with operational research evidence as well as co-develop recommendations based on evidence; and strengthen national and local capacity for integrated analytics approaches.³⁶ The core objective was to identify gaps in information on the outbreak to improve response, though each individual study could have more specific research questions.

If relevant data exists, CAI's central team of national and international researchers will collate and process the data to the extent possible. Relevant data can include "qualitative and quantitative data on health services, perceptions and behaviors of the communities (people), staff of health and care (availability, risk, changes), events and chronology (policies, restriction, information, response strategies), and markets, prices and the socio-political context (possible conflicts, gender dynamics, culture)."³⁷ It may include data on Health Information Systems (HIS) data (stored using District Health Information Software (DHIS2), and other systems.³⁸ Using other actors' data is part of the CAI's strategy to avoid unnecessary and duplicative data collection whenever possible.³⁹ The team will also assist government officials and other partners (e.g. civil society, local and international NGOs) in making sense of this data to pull our major trends and using it to co-develop recommendations and bring together data sources to better understand epidemic dynamics and public health outcomes.⁴⁰

If relevant data is absent and that need can be filled by information available in the field, then CAI works with local researchers who are trusted by communities to collect this data. Local researchers are trained and supported by the CAI national and international teams. The majority of the CAI researchers are hired locally and operate without UN insignias or logos, instead operating under the umbrella and in collaboration with the national MoH. Using community interviews, surveys, and similar methods, teams collect data on community health. All the CAI members commit to completing training sessions to enforce ethical

³⁶ Cellule d'analyse en sciences sociales. "Recommandations Issues de La Recherche En Sciences Sociales: Cadre de Redevabilité Pour Les Programmes UNICEF." Google Docs, February 28, 2020. <u>https://docs.google.com/</u> <u>document/u/3/d/1zyQQpHRhKmjq2MIcb5-DaH66VvNY2IfTtmiM0I3JGh4/edit</u>.

³⁷ Cellule d'analyse en sciences sociales. "«Comment Créer Une CASS?»: Aspects Clefs et Ressources Existantes: Sur La Base Des Expériences de l'épidémie d'Ebola Au Nord-Kivu et Ituri (Août 2018-Avril 2020)." April 11, 2020. <u>https://docs.google.com/presentation/d/1tr4dZ1tmrXmeRciH6cxfill52ZNBSLzt</u>.

³⁸ DHIS2 is an open source software platform used by more than 60 countries. See: DHIS2. "Home." Accessed August 23, 2022. <u>https://dhis2.org/</u>.

³⁹ Integrated Outbreak Analytics (IOA), CASS & GOARN. (2021, June 21). What is Integrated Outbreak Analytics and the CASS (DRC) [Video]. YouTube. <u>https://www.youtube.com/watch?v=7SI7e24iKk4</u>

⁴⁰ Cellule d'analyse en sciences sociales, *supra* note 39.

deployment. Using data-analysis programs such as Atlas-ti, NVivo, Epilnfo and SPSS, analysts apply quantitative and qualitative research methods and interpret the data.47 Tools also include using Excel Spreadsheets to create easy to access and analyze dashboards and functionalities on Google Drive may also

All this work goes toward the production of case studies that succinctly summarize the dynamics contributing to the outbreak or epidemic for a decisionmaker. Data is first presented by the CAI at a local level, and then subsequently used to co-author studies on local policy effects and needs with local, national, and international stakeholders. Teams execute the studies at a very fast pace, with most studies taking 7–25 days from when teams identify the key question to completion depending on the question and methodology applied. Studies look at factors and dynamics identified alongside important contextual factors such as timelines, events, border closures, political development, and/or events that may directly affect the outcomes of an epidemic). They also

be applied as needed.48

considerations before the program starts. They also conduct regular trainings with the CAI research teams to ensure that everyone understands ethical research practice and how to report, raise, and refer any protection related cases (including gender-based violence).41

The CAI operational and adapted studies seek to better understand why a particular trend or situation is occurring in a particular location at that moment.⁴² Interviews always begin by asking participants for consent and giving context on the study and use of the data.43 The CAI team does not collect any unique identifiers. The CAI findings are stored on a Google Drive and made accessible to the Minister of Health and partners.44 Over the course of its initial set up during the tenth EVD outbreak, in the DRC the CAI conducted 57 field studies⁴⁵ focused on issues such as why certain groups did and did not seek treatment.⁴⁶ All information, whether gathered from existing sources or collected from the field, is then reviewed and analyzed by the CAI team to answer the questions raised at the start of the

⁴¹ Carter, Simone. RD4C Interview: CASS/EpiCell/IOA. Zoom, November 23, 2021.

⁴² Carter, Simone. CAI follow-up interview. Zoom, May 31, 2022.

⁴³ Ibid.

⁴⁴ Ibid

⁴⁵ CASS, 2022. Social Science Support for COVID-19: Lessons Learned Brief 4. [online] CELLULE D'ANALYSE EN SCIENCES SOCIALES. Available at: https://www.unicef.org/drcongo/media/4141/file/CASS-Brief4-barriers.pdf.

⁴⁶ Cellule d'analyse en sciences sociales. "PRESENTATION EN DRAFT SUR LES RAISONS DES DELAIS DANS LES ITINÉRAIRES THÉRAPEUTIQUES." Goma, Democratic Republic of the Congo, September 9, 2019. https:// docs.google.com/presentation/d/1ttVCdwpWsy5EhYxx6gawHB4t65Y28pn9.

⁴⁷ Carter, et al. *supra* note 35.

⁴⁸ Carter, supra note 42.

take into account cultural norms and gender roles and dynamics, and the interaction of all these types of data.⁴⁹ When study results are ready, the results are presented to local actors (e.g. civil society, community health workers, local and international NGOs, the MoH and other UN actors) to co-develop recommendations. As noted, the frequency of these presentations vary, though for the EVD response they occurred weekly. Presentation styles

could vary depending on the particular audience (e.g. healthcare workers, senior government leaders).⁵⁰

The recommendation co-development process takes place through a structured process facilitated through an Excel tool called MONITO.⁵¹ This tool, developed through an iterative process, allows the tracking of recommendations over time, by location, and by disease.⁵²

The co-development and monitoring process 1 - Presentation of the results to research team : does the analyses reflect reality? How can it be interpreted? Limitations? 2 - Presentation of the results to the Ministry of Health management validation and feedback** (usually full presentation of results) 3 - Validation and modification of the presentation for different actors 4 - Presentation of the results to all stakeholders and response actors: co-development of recommendations, actions, indicators, timeframe for implementation Integration in the recommendation monitoring tool (MONITO) Influence response strategies or approaches

FIGURE 3: The MONITO cycle, as provided by the CAI team.

⁴⁹ Carter, Simone. RD4C Interview: CASS/EpiCell/IOA. Zoom, November 23, 2021.

⁵⁰ "What Is the IOA Approach for Decision-Making in Public Health Emergencies? (ENG)" supra note 34.

⁵¹ Cellule d'analyse en sciences sociales. "Le suivi de l'utilisation des evidences pour influencer la réponse aux urgences de santé publique." Google Docs, August 9, 2021. <u>https://drive.google.com/file/d/16QZfx3OWz-ss30cYikCj0OM5vCunMoHd/view?usp=sharing</u>.

⁵² Cellule d'analyse en sciences sociales. "2020-04 FINAL MONITO EBOLA 2018-20.Xlsx." Google Docs, August

^{5, 2020.} https://docs.google.com/spreadsheets/u/3/d/11a9YdUsrBhCP06GtuA3LCPpy5cdhUvLZ/edit.

It helps associate particular needs with specific actions that can address them. MONITO works as follows: While in the field, the local research teams present findings to the different partners and codevelop recommendations. Each recommendation may have multiple activities to achieve it. The CAI team works with actors to agree on indicators to follow up on the agreed actions along with a timeline. The co-developed recommendations and activities are written onto a form and shared with the CAI MONITO supervisor who enters the information into an Excel spreadsheet for easy monitoring. The study results are presented at the local and provincial level with other clusters and key partners. Each presentation is organized with the objective to use evidence and build recommendations with these actors.

The MONITO supervisor regularly follows the tool to identify when teams should go back to partners to check if the actions have been completed (based on the agreed indicator). This evaluation also allows the team to track the number of recommendations put forth. It also allows for assessment of the recommendations by types of public health issues, by study, by locations and by type of actors or sectors (e.g. WaSH or health or Risk Communication and Community Engagement) over time. The CAI teams regularly share reports with progress on the use of evidence over time and by public health concern.

As described by staff, the methods used by CAI represent a paradigm shift in how the UN and its organizational partners use social sciences and other data sources and methods to support outbreak response. The unit's development of the IOA approach allows it to look more holistically at data in outbreaks and to understand specific trends and patterns in spread. This datainformed approach has increasingly become the norm for the DRC's MoH and key partners in responding to EVD and other public health emergencies.

Moreover, research suggests that the multi-disciplinary approach has helped socialize these practices more broadly. As noted throughout, CAI brings together a variety of experts including bio-medical epidemiologists, medical anthropologists, data scientists and modelers, government personnel, and others. This inclusive approach allows lessons to disseminate quickly within an institution through the many different actors involved in the field.⁵³ Personnel suggest this work is creating new norms about the integration of the perspectives of affected communities in outbreak response. It is also encouraging organizations to think about how responses to public health incidents

⁵³ Cellule d'analyse en sciences sociales. "Presentation of the CASS." Google Docs, April 17, 2020. https:// docs.google.com/document/u/3/d/1IZki-j8CAirg_f9Rbjx-6kd1UcOnvGnb/edit.

Another positive organizational impact was linked to the "no-logo" approach, through which CAI worked in service of the DRC MoH and partners to ensure that the only branding on presentations and products is that of the national ministry of health. This has meant that different actors are more keen to share their data and contribute to a platform rather than have their data rebranded under the UN. As well, all the CAI data and tools were made online and open access. This approach facilitated cooperation between organizations and helped address trust and legitimacy issues in the field, and allowed for additional initiatives to gain inspiration for their own data models, tools, and disclosure practices. This was possible mainly due to the lack of specific funding or stringent data requirements from donor partners, which permitted the use of data that was already available and the inclusion of other partners in the research. 54

Finally, CAI has been seen as a useful way of testing new tools and generating actionable insights. According to field reporting, more than 250 evidencebased changes were implemented with the help of the MONITO tool in 2021 alone.⁵⁵

OUTCOMES IN THE FIELD

In terms of promoting public value, the original overarching goal of CAI (at the time known as CASS) in 2018 was "to contribute to a swift end to the Ebola outbreak by integrating epidemiological analyses with evidence on social and behavioral perspectives and drivers to better understand outbreak dynamics and inform response strategies and activities."56 In service of this objective, CAI conducted 57 field studies, and together with the MoH and response actors, developed 112 recommendations. Action on these recommendations, in the view of staff, helped manage and contain the outbreak in the provinces of North Kivu and Ituri.

Many of these recommendations were co-developed through presentations that made the insights understandable and actionable for decision-makers. CAI supported the rapid production of systematic and operational evidence, which was helpful to inform response activities. The CAI leadership reported that the establishment of CAI helped to "better understand broader health dynamics influencing the Ebola outbreak and community health outcomes

⁵⁴ Ibid.

⁵⁵ Carter, supra note 42.

⁵⁶ Carter SE, Ahuka-Mundeke S, Pfaffmann Zambruni J, *et al*How to improve outbreak response: a case study of integrated outbreak analytics from Ebola in Eastern Democratic Republic of the Congo*BMJ Global Health* 2021;6:e006736. <u>https://gh.bmj.com/content/6/8/e006736</u>

resulting from the outbreak."57 It created space for the integration and use of data on health services and health outcome reports from healthcare facilities across the country.

This approach also supported better public communication around EVD. After uncovering that many children under the age of five infected with EVD were not quickly diagnosed, CAI conducted interviews with parents and healthcare workers. These interviews revealed that many parents did not realize their children were exhibiting symptoms of EVD and that many healthcare workers found it difficult to detect symptoms among children themselves.58 Pictures and posters of hemorrhagic symptoms were removed as the materials were redesigned and re-developed to more appropriately represent EVD symptoms (fever, body aches). This was critical in removing the misunderstanding of the disease symptoms and reinforcing healthcare seeking behavior and trust in diagnoses. The study also proved instrumental in revealing that many healthcare facilities did not have adequate resources to care for higher than expected numbers of sick children and that transmission was facilitated

through children sharing beds within care facilities.⁵⁹ CAI partners reduce bed sharing, promote vaccination, and promote decontamination procedures.⁶⁰

Based on its perceived success in DRC, the CAI has been used to support response to COVID-19 in the DRC and across sub-Saharan Africa.⁶¹ The CAI's research on the broader impacts of COVID-19, which highlighted the negative impacts of school closures on gender based violence, increased under-age pregnancy and child labour, contributed to the reopening of schools in the country. The CAI team also conducted a study looking at the impacts of COVID-19 on family planning which highlighted an increase in underage pregnancies in Kinshasa, about Government of the Democratic Republic of Congo months after school closure and lockdowns. Consequently, international organizations reinforced their partnership programs regarding family planning, mobile clinics, and access to free family planning in areas that were previously mostly urban, or peri-urban and low income.⁶²

⁵⁷ Ibid.

⁵⁸ Integrated Outbreak Analytics (IOA) GOARN, *supra* note 12.

⁵⁹ Ibid.

⁶⁰ Ibid.

⁶¹ CELLULE D'ANALYSE EN SCIENCES SOCIALES | CASS, 2020. Social Science Support for COVID-19: Lessons Learned Brief 3. [online] CASS. Available at: https://www.unicef.org/drcongo/media/4131/file/CAI-Brief3recommendations.pdf.

⁶² Carter, supra note 42.

V. INSIGHTS RELEVANT FOR ADVANCING RD4C LOCALLY AND GLOBALLY

The CAI demonstrates several prominent values that other organizations might try to embody in their own work:

- Proportional: The CAI team only collects data when they can be sure it will be relevant and used. The team involves the data users from the outset so that it is not overburdening communities to participate in studies that don't have operational use. CAI also ensures that it uses locally identified and trusted researchers—women working with women and men with men, but also specific members of communities. The team does not collect information to document suffering as it is beyond the specific scope of operational research or data if it can find another study providing "good enough" or similar work, in order not to collect unnecessary or excessive amounts of data.⁶³
- Participatory: The CAI's approach towards data collection is highly participatory as it engages a variety of actors working in the health sector in the country, including the local government. The data collected by the program is the property of the MoH while also the data is made accessible to all, despite challenging internet connectivity. Furthermore, data collectors are locals and data collection is done in the local language, with consent from data subjects obtained prior to collection.
- Purpose-driven: The data collected by the CAI team has been motivated by specific needs, as shown in the outcomes section of the case study. During the tenth EVD outbreak, CAI study results led to the development of some 112 recommendations, some of which—such as the ones regarding communications materials—enabled a shift in how the disease was perceived in the country and enabled the reopening of schools. Following from the success of this model, the CAI aims to replicate it across several countries in Sub-Saharan Africa, adapting to new contexts presented by outbreaks such as the current COVID-19 pandemic.

A. Barriers to RD4C

Infrastructure and connectivity challenges: Issues with internet connection and the need to ensure data was available to MoH and all partners led the CAI team to store its data on Google Drive, which presents confidentiality and security issues. While the team has tried to shift to a more secure form of cloud storage, such as Pcloud, this has been complicated by the open nature of the data sharing and the low levels of connectivity as well as internet infrastructure.

This reliance on Google Drive is particularly problematic with databases of contacts, contact tracing or vaccination and the team has struggled with bridging the need for both safety and accessibility in poorly-connected areas that cannot maintain solely online access to sensitive data. In the words of the program lead, "As soon as you get to outside capital areas, if you want to protect data, it's not analyzed locally. This becomes very challenging. When there's no good internet, when there's absolutely no capacity to share data safely."

The team is seeking out ways to reinforce capacity to safely store the data belonging to the Ministries of Health while also refraining from "imposing very High-Income approaches to data protection that cannot be applied in these contexts."⁶⁴ While some issues may be inevitable given the context, stakeholders might work to define clear strategies and procedures for maintaining responsibility and ensuring that the data is as protected as possible while navigating these challenges.

- Competing Interests Around Data Use: The CAI team also admitted to being faced with competing interests from its many partners with various groups seeking to use the data to influence and inform it at their own level and in their own way. Staff discussed at length the political aspects of epidemiological work and resulting challenges when it comes to ensuring the right data is collected and shared. It might be beneficial to develop a set of principles, guidelines, and standards for CAI in coordination with partners to ensure that all work adheres to certain ethical requirements.
- Limited Data Expertise: In addition, CAI teams mentioned the lack of practice regarding data security norms. These practices led to cases in which unique identifiers of individuals were shared in WhatsApp groups or other unsecure platforms.⁶⁵ The teams could benefit from classifying information by risk and sensitivity. Once assessed, risk ratings can then be used to standardize how information is protected. In addition, the team could ensure that only authorized personnel have access to children's information. Special measures should also be

⁶⁴ ibid.

⁶⁵ Ibid.

Referrals for ethically challenging cases: During its work, the The CAI team sometimes faced difficult ethical situations that required referral. The local teams were not always knowledgeable on what procedures to follow. An interviewee mentioned the example of staff struggling to respond to "young girls who were exchanging sex for coupons for water" and how to best report the case.⁶⁶ Frequent exchanges are organized to remind teams about gender-based violence as well as how to report instances of it. However, an interviewee noted that these practices are not always ingrained in day-to-day activities. Staff noted that certain problematic cases may come up during the analysis phase and raise possible questions about why they were not flagged earlier. CAI staff further stated that these examples pose real challenges for the safety of the individuals concerned.

Many of these challenges would be mitigated through additional resources through which to hire more staff and material. A special, designated team responsible for oversight of particularly complex cases could be beneficial. In lieu of this, staff might see how they can reinforce existing ethics processes and training procedures. CAI might create further accountability by requiring individuals to document how and why they acted in certain ways with regards to certain specific cases. This transparency can, in turn, help organizations identify best practices, understand possible sources of dysfunction, and remain accountable to those they serve. By gathering this information, staff might identify good practices for handling cases and standardize them. Codifying good practice creates consistency across teams, improving coordination.

CONCLUSION

Despite infrastructure and capacity challenges, the CAI is seen as a very successful initiative in the DRC and it was maintained and expanded to work on numerous new diseases. Its work and innovative approach to epidemiological research has been recognized by both the Congolese government and stakeholders abroad and has led to tangible outcomes in targeting response policies and communications. As its host countries continue to face epidemics, CAI will likely see continued improvements as it iterates how it understands the various elements influencing the propagation of diseases.

The CAI teams continue to seek to reinforce its existing RD4C values. Its work has proven to be participatory, as it includes stakeholders from various backgrounds, proportional, as only limited and necessary amounts of data are collected and purpose-driven, as it focuses on using IOA methods and data to inform policy recommendations that address the public health issue at hand. While a lack of resources and contextual constraints have made the CAI team's approach to responsible data handling more challenging, teams continue to seek solutions and to implement clearer strategies and procedures for maintaining responsibility as well as special measures to protect against unintended and unrestricted access. In addition, the team continues work towards more transparency and accountability all while identifying and rewarding good practices.



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