



Dissemination and **academic?** publication of research findings during epidemics

Bruce J Kirenga

Background

- Corona virus disease 2019 (COVID 19), a disease caused by the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) virus, was first reported in early December 2019 in Wuhan China
- The pandemic has disrupted nearly every aspect of normal life across the globe
- Research in all its spheres could not have been spared
- There was a 65% worldwide average decrease in new patient enrollment year-over-year during March 2020
- Changed funding landscape- most funding prioritized for COVID 19.
- New approaches to dissemination of research findings emerged with advantages and disadvantages

Dissemination

- **Dissemination** refers to the process of sharing **research** findings with stakeholders and wider audiences.
- NIHR defines dissemination “**getting the findings of your research to the people who can make use of them, to maximise the benefit of the research without delay.**”
- **In pandemics dissemination is not business as usual!!**
- Uncertainty can trigger negative feelings, such as stress and anxiety , and may cause people to engage in various communication behaviors, such as actively seeking information
- Dissemination is **a learned response to stress**; in uncertain circumstances, dissemination activities are frequent.
- Uncertainty in public health emergency includes three dimensions:
 - global health uncertainty, which is a “gap” in existing scientific knowledge about the pathogen;
 - public health uncertainty, which is the difficulty in determining the epidemiological risk distribution;
 - clinical uncertainty, which refers to whether effective treatment can be provided

Common methods of dissemination

1. Journal articles
 2. Program or policy briefs.
 3. Presentations at conferences and scientific meetings
- *the three Ps, posters, presentations, and papers*
 - 4. Non academic disseminations; presenting results to wider audiences – social media, pressers, TV & radio interviews.

Journals

- Several publishers and prestigious journals have invited and prioritized the COVID-19-related scientific reports
- 100 academic journals, societies, institutes, and companies have entered an agreement—based on the 2016 Statement on Data Sharing in Public Health Emergencies—to make the research and data on COVID-19 publicly available, at least until the outbreak lasts
- Even big journals-The Lancet, The New England Journal of Medicine, Oxford University Press etc

PONE-D-20-33479

Feasibility of collecting and processing of COVID-19 convalescent plasma for treatment of COVID-19 in Uganda
PLOS ONE

Dear Dr Kirenga,

As part of an initiative between PLOS (and other publishers) and the World Health Organization (WHO) to ensure that all relevant clinical information about this outbreak is

shared quickly, I am writing to let you know that we will provide the WHO with a copy of your manuscript in the next 2 days. More information on this initiative can be found here:

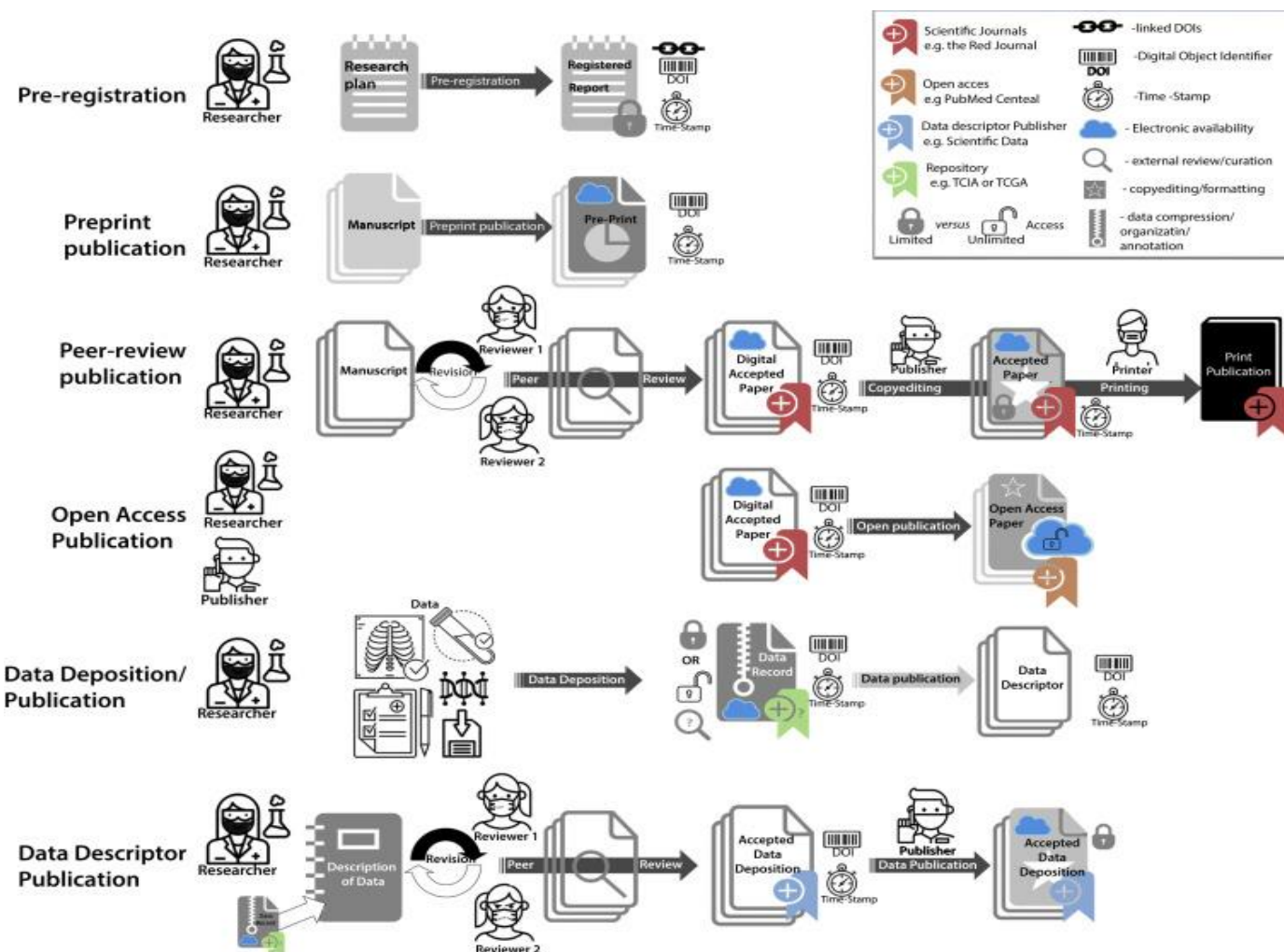
<https://wellcome.ac.uk/press-release/sharing-research-data-and-findings-relevant-novel-coronavirus-covid-19-outbreak>.

If you have an existing preprint of your manuscript posted, we will simply notify the WHO of the preprint identifier. If you have not already done so, we would encourage you to deposit your manuscript in a public preprint server. We would recommend the preprint server medRxiv (<https://www.medrxiv.org/>), which posts clinically relevant manuscripts. This process is free of charge.

Wellcome press release | 31 January 2020

- **Sharing research data and findings relevant to the novel coronavirus (COVID-19) outbreak**
- The [outbreak of the novel coronavirus \(COVID-19\)](#) represents a significant and urgent threat to global health.
- **We call on researchers, journals and funders to ensure that research findings and data relevant to this outbreak are shared rapidly and openly to inform the public health response and help save lives.**
- We affirm the commitment to the principles set out in the 2016 [Statement on data sharing in public health emergencies](#), and will seek to ensure that the World Health Organization (WHO) has rapid access to emerging findings that could aid the global response.
- Specifically, we commit to work together to help ensure:
 - all peer-reviewed research publications relevant to the outbreak are made immediately open access, or freely available at least for the duration of the outbreak
 - research findings relevant to the outbreak are shared immediately with the WHO upon journal submission, by the journal and with author knowledge
 - research findings are made available via preprint servers before journal publication, or via platforms that make papers openly accessible before peer review, with clear statements regarding the availability of underlying data
 - researchers share interim and final research data relating to the outbreak, together with protocols and standards used to collect the data, as rapidly and widely as possible - including with public health and research communities and the WHO
 - authors are clear that data or preprints shared ahead of submission will not pre-empt its publication in these journals

Graphical representation of current disparate and independent scientific dissemination processes, showing actors, activities, and component documents/data/software.



Fuller CD, van Dijk LV, Thompson RF, Scott JG, Ludmir EB, Thomas CR. Meeting the Challenge of Scientific Dissemination in the Era of COVID-19: Toward a Modular Approach to Knowledge-Sharing for Radiation Oncology. *International journal of radiation oncology, biology, physics*. 2020 Oct 1;108(2):496-505.

Advantages and disadvantages

- Advantages

- Fast availability results to clinicians, policy makers and scientists.
- Rapidly sharing scientific information **is an effective way to reduce public panic**, and it is the key to providing real-time guidance to epidemiologists working to contain the outbreak, clinicians managing patients, and modelers helping to understand future developments and the possible effectiveness of various interventions.
- Academic benefits to authors and researchers

- Disadvantages

- Publication of **unscrutinized**, COVID-19-related manuscripts have been submitted to preprint servers such as medRxiv
- the management of the pandemic may be jeopardized by the rapid and uncontrolled dissemination of clinical data- **hampering of ongoing trials- rushed guidelines, patient refusal to participate** etc

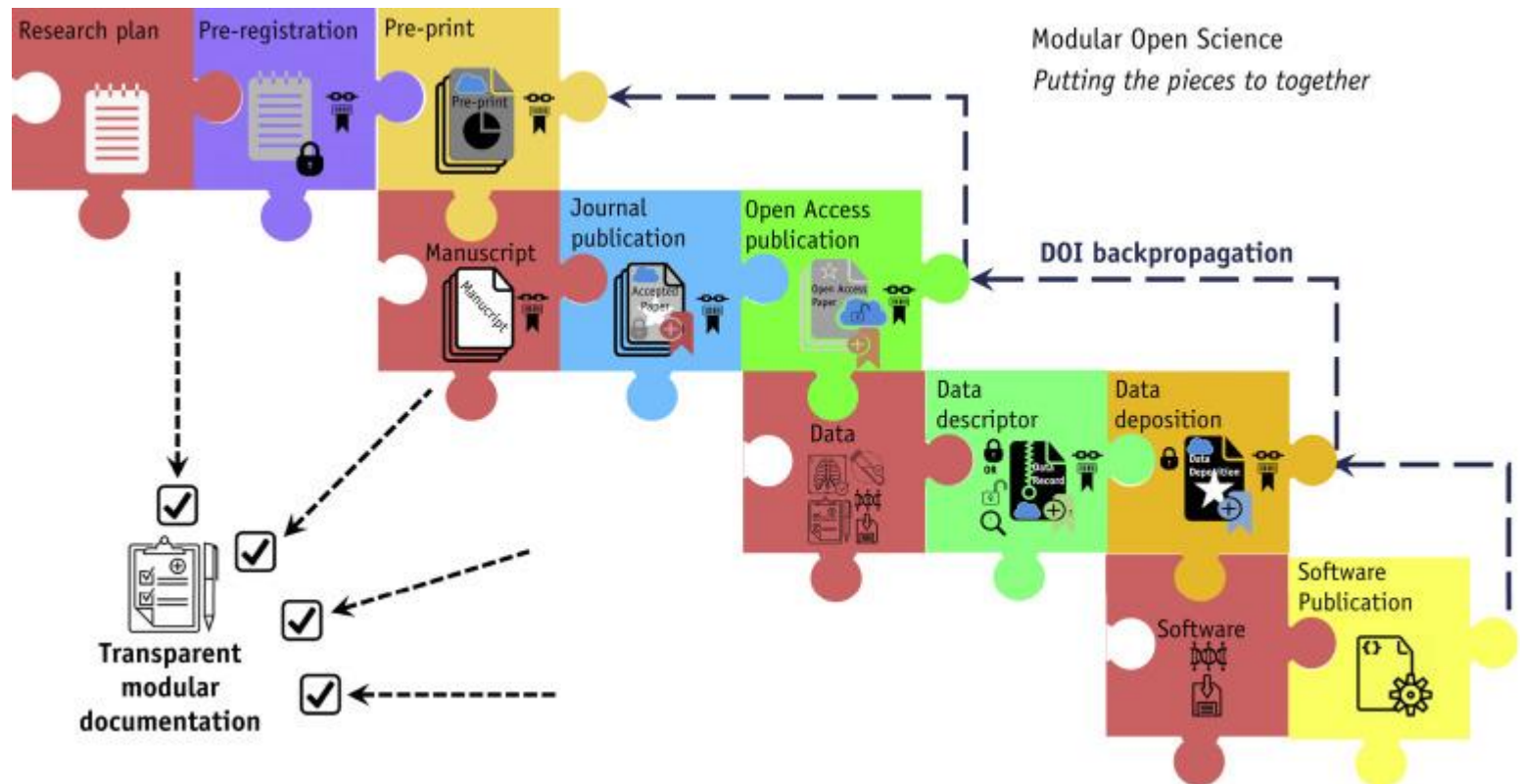
Scenario

- On May 1 and May 22, 2020, a pair of high-profile articles were fast-track reviewed and published by the *New England Journal of Medicine (NEJM)* and *The Lancet*, venues widely regarded as among the most prestigious of medical journals.
- The *Lancet* article reported a multinational registry analysis of chloroquine with or without macrolide antibiotics in patients who were infected with the novel severe acute respiratory syndrome corona virus-2 virus, and an *NEJM* manuscript from the same group investigated angiotensin-converting enzyme inhibitors and angiotensin-receptor blockers in patients who tested positive for coronavirus disease 2019 (COVID-19).
- These papers would have been a pinnacle achievement for the academic coauthors, in addition to the supporting company Surgisphere, who reportedly supplied the data.
- Led by the vascular surgeon Sapan Desai, this small company with “big data” aspirations redefined research priorities and patient study allocation with their remarkable results. Unfortunately, these august journals would soon be roiled by controversy when it became evident that the data may have been falsified for both papers.
- The subsequent debacle serves as a cautionary tale of the systematic failure modes of traditional avenues of sharing and verifying clinical science, particularly when applied to fast-tracked research.

Cont'd

- Warning signs regarding the scientific integrity of these publications were posted not in a traditional journal, but via the *Zenodo* preprint server, as a near-immediate open letter to the *Lancet*.
- Statistician James Watson led signatories to critique the *Lancet* and *NEJM*'s fidelity to their own policies on data transparency, noting, among other issues: "the [Surgisphere] authors have not adhered to standard practices in the machine learning and statistics community.
- They have not released their code or data" nor external study preregistration with an ethics board. The letter demanded "Surgisphere provide[s] details on data provenance, [with] independent validation of the analysis [and] open access to all the data sharing agreements cited above..." to verify findings in the *Lancet* article.
- *A retraction of the Lancet article followed, as the data could not be verified. In early June 2020, the results in NEJM were similarly repudiated, "after concerns were raised with respect to the veracity of the data and analyses conducted by Surgisphere Corporation."*

Proposed transparent modular scientific dissemination process



Fuller CD, van Dijk LV, Thompson RF, Scott JG, Ludmir EB, Thomas CR. Meeting the Challenge of Scientific Dissemination in the Era of COVID-19: Toward a Modular Approach to Knowledge-Sharing for Radiation Oncology. *International journal of radiation oncology, biology, physics*. 2020 Oct 1;108(2):496-505.

Data sharing; The FAIR guiding principles

Wilkinson MD, Dumontier M, Aalbersberg IJ, Appleton G, Axton M, Baak A, Blomberg N, Boiten JW, da Silva Santos LB, Bourne PE, Bouwman J. The FAIR Guiding Principles for scientific data management and stewardship. Scientific data. 2016 Mar 15;3(1):1-9.

Principles	Concepts
To be Findable:	<p>F1. (Meta)data are assigned a globally unique and persistent identifier</p> <p>F2. Data are described with rich metadata (defined by R1 below)</p> <p>F3. Metadata clearly and explicitly include the identifier of the data it describes</p> <p>F4. (Meta)data are registered or indexed in a searchable resource</p>
To be Accessible:	<p>A1. (Meta)data are retrievable by their identifier using a standardized communications protocol</p> <p>A1.1 The protocol is open, free, and universally implementable</p> <p>A1.2 The protocol allows for an authentication and authorization procedure, where necessary</p> <p>A2. Metadata are accessible, even when the data are no longer available</p>
To be Interoperable:	<p>I1. (Meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation</p> <p>I2. (Meta)data use vocabularies that follow FAIR principles</p> <p>I3. (Meta)data include qualified references to other (meta)data</p>
To be Reusable:	<p>R1. Meta(data) are richly described with a plurality of accurate and relevant attributes</p> <p>R1.1. (Meta)data are released with a clear and accessible data usage license</p> <p>R1.2. (Meta)data are associated with detailed provenance</p> <p>R1.3. (Meta)data meet domain-relevant community standards</p>

Social Media Use

Social media is not a traditional way to disseminate research information

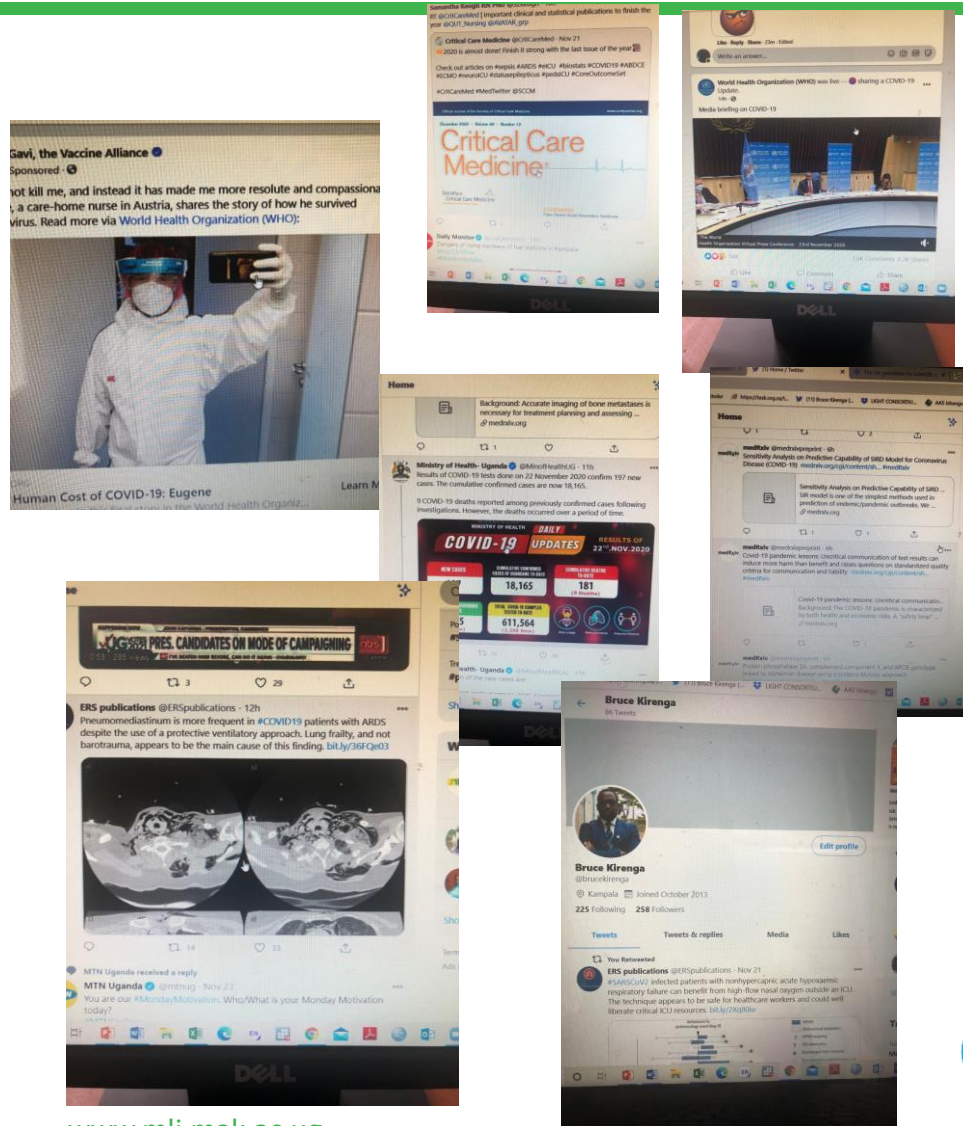
However its increasingly used more so in pandemics because it creates information liberation

Many big journals, organizations, news channels now operate social media pages

Many executives and scientists now operate social media pages especially twitter

Many researchers are identifying advantages in information dissemination on social media.

Information on WhatsApp, YouTube, and Facebook can help health professionals refresh their knowledge; it is also useful for their career development.



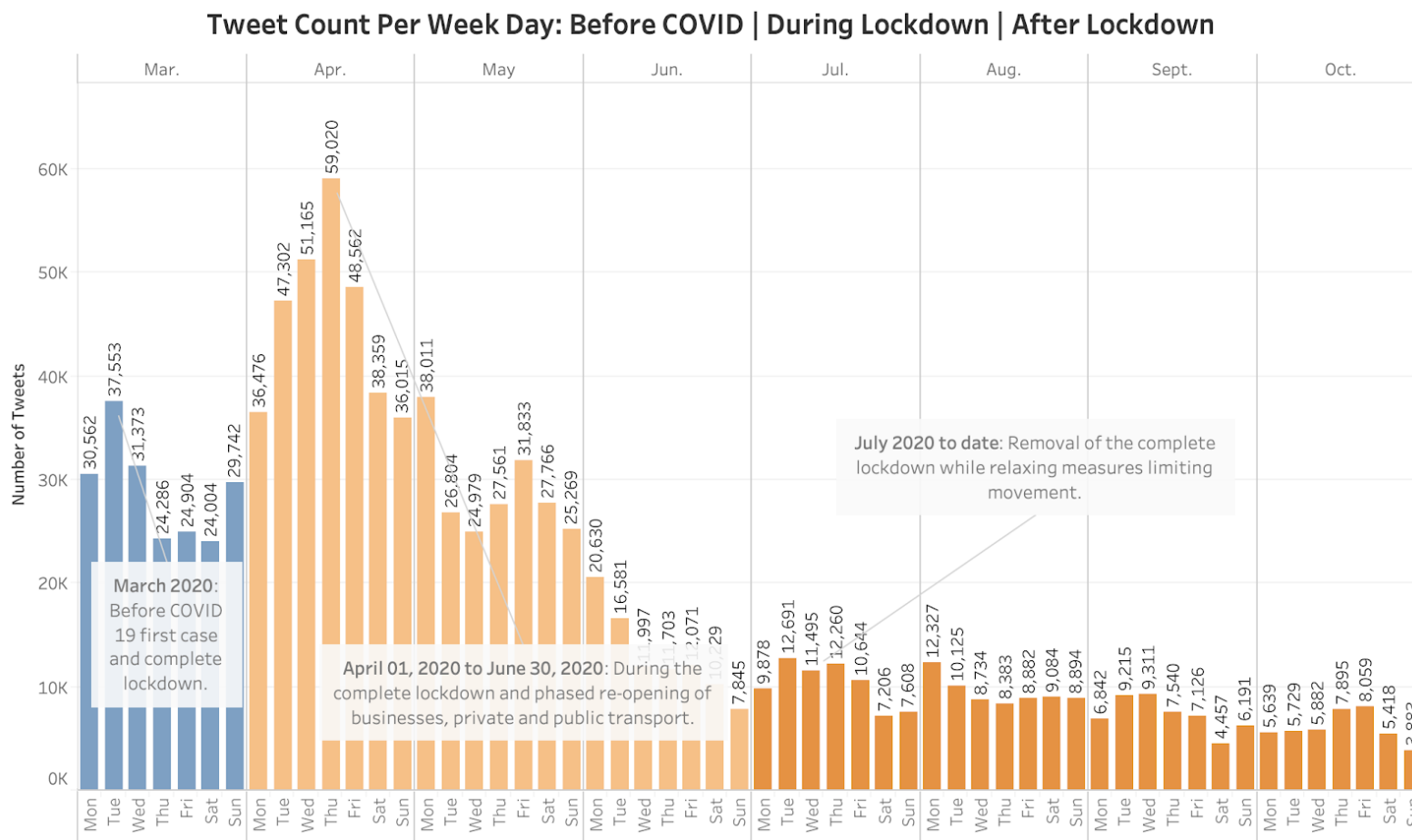
Pandemics in the Age of Twitter: Content Analysis of Tweets during the 2009 H1N1 Outbreak

Cynthia Chew^{1,2}, Gunther Eysenbach^{1,2*}

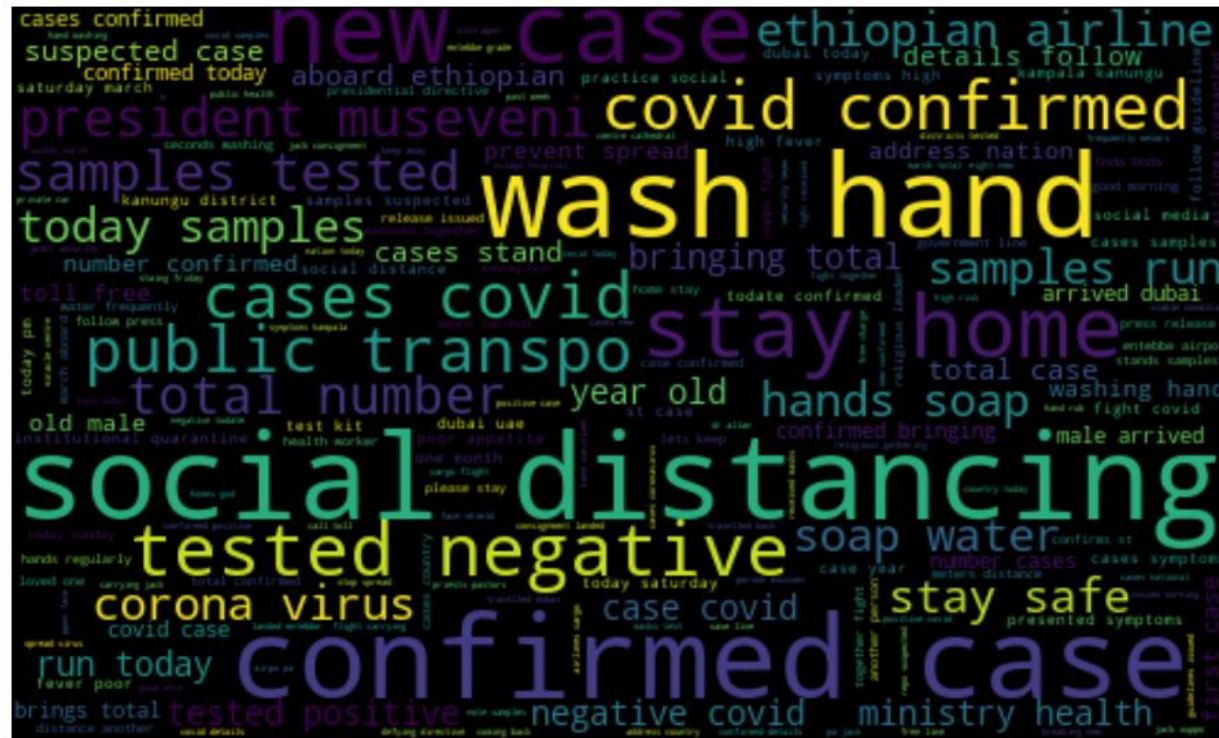
¹Centre for Global eHealth Innovation, University Health Network, Toronto, Canada, ²Department of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto, Canada

- This study illustrates the potential of using social media to conduct “infodemiology” studies for public health.
- 2009 H1N1-related tweets were primarily used to disseminate information from credible sources, but were also a source of opinions and experiences. Tweets can be used for real-time content analysis and knowledge translation research, allowing health authorities to respond to public concerns.

Mining of social media to Inform COVID-19 Response in Uganda



Slides kindly provided by Agnes Kiragga, PhD Email: akiragga@idi.co.ug, Twitter: @agnes_kiragga, Infectious Diseases Institute
African Center of Excellence in Bioinformatics and Data Science, Makerere University, Kampala, Uganda



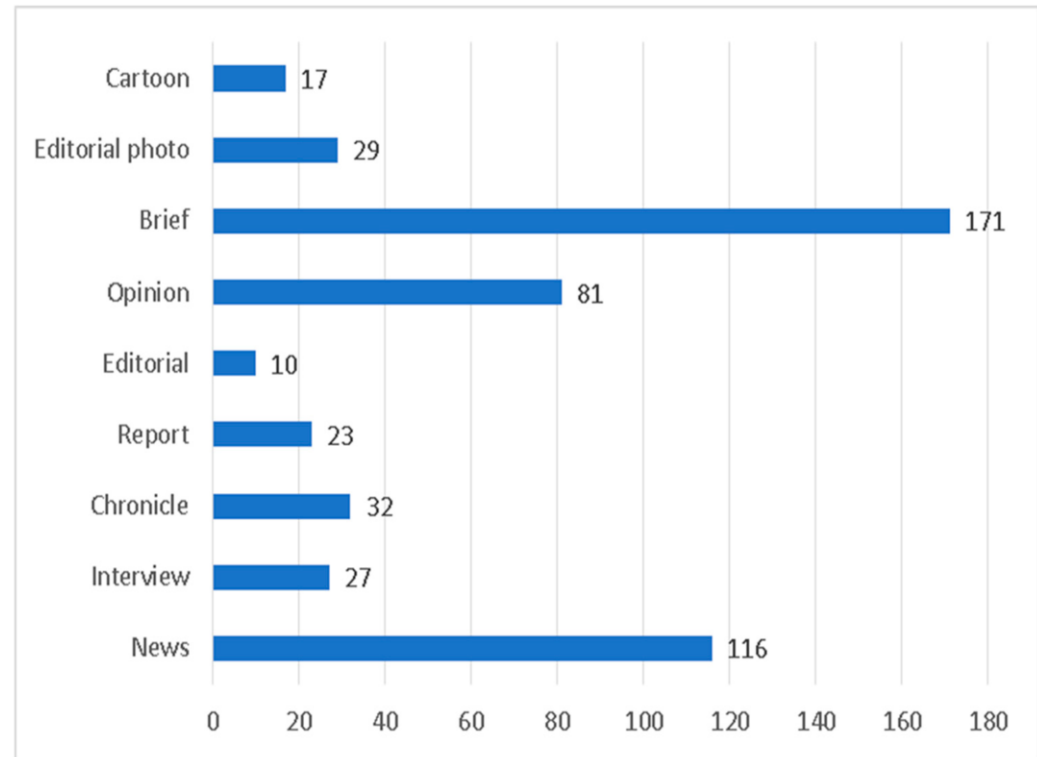
Traditional media-TV, radio newspapers

Traditional print and broadcast media play a role in dissemination of research findings for the general public in pandemics

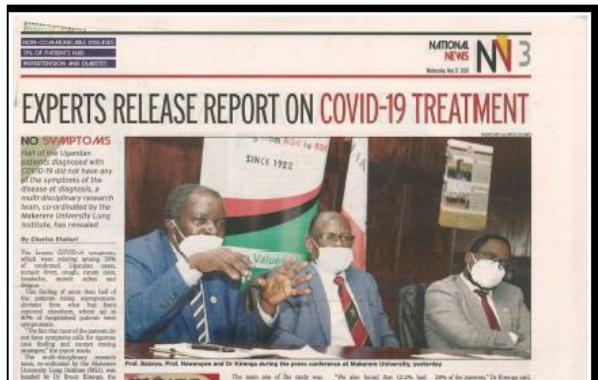
In Italy a study with the aim of understanding how the corona crisis has been represented in Spanish and Italian media

Results show a predominance of informative journalistic genres (especially brief and news), while the visual framing emerging from the photographic choice, tend to foster humanization through an emotional representation of the pandemic

Politicians are the most represented actors, showing a high degree of politicization of the crisis



Pressers



Thank you

Science for Healthy Lungs