

Community-Centered User Research for the Development of the WHO's Epidemic and Pandemic Preparedness Platform, the Hive

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Abstract. Each epidemic and pandemic is accompanied by an infodemic. The infodemic during the COVID-19 pandemic was unprecedented. Accessing accurate information was difficult and misinformation harmed the pandemic response, the health of individuals and trust in science, governments and societies. WHO is building a community-centered information platform, the Hive, to deliver on the vision of ensuring that all people everywhere have access to the right information, at the right time, in the right format in order to make decisions to protect their health and the health of others. The platform provides a safe space for knowledge-sharing, discussion, collaboration, and access to credible information. The Hive platform is an innovative minimum viable product that seeks to leverage the complex information ecosystem and the invaluable role of communities to share and access trustworthy health information during epidemics and pandemics.

Keywords. Trustworthy information, epidemic and pandemic response, health information platform, machine-learning

1. Introduction

In today's highly interconnected world, each individual is exposed to a complex information ecosystem, further exacerbated during an acute health event. An *infodemic* is an overabundance of information, accurate or not, that spans both the digital and physical space, often accompanying an outbreak or epidemic [1]. During epidemics and pandemics, the evolving situation, increase in uncertainty and need for individuals to make decisions rapidly can make accessing timely information difficult. The first six months of the pandemic saw an unprecedented increase in the volume of scientific information with more than 20,000 COVID-19 related articles published [2]. Many of the articles were generated rapidly without adequate scientific rigor, and peer review. Furthermore, as scientific knowledge evolved, this evolution was often not explained well. Many voices and opinions debating the science and accompanying policies, often

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led to polarizing debates. In some cases, response measures were politicized and media content sensationalized, which amplified uncertainty and fear within societies. Under these circumstances, it was difficult for people to access trustworthy information to make decisions to protect their health and the health of their communities. All of these aspects of the infodemic impacted trust within societies, thereby negatively impacting pandemic response efforts. As a result, the global health community has been looking for solutions to improve access to trustworthy information, increase health and scientific literacy, and facilitate individual and community decision-making while promoting autonomy and localization of epidemic and pandemic responses.

1.1. Trust for Epidemic and Pandemic Preparedness and Response

The aim of this paper is to describe how the collection of data and crowdsourced solutions can inform the development of a platform to build trust within communities. Trust as a social capital is fragile, particularly in times of crisis. It requires specific, intentional interventions for it to be nurtured and maintained. Communities and individuals need to be listened to and able to participate in broader discussions to share and understand the challenges and impediments they are facing together. Ultimately communities are where trust is built, information is shared, and collaboration happens. Particularly in times of crisis and uncertainty, people turn to those who have remained trustworthy over time. To develop and maintain trust across communities, autonomy, consistency, transparency in communication, underpinned by the accountability of leaders and decision-makers, and active community involvement are essential.

1.2. Listening to Communities

WHO uses several strategies to disseminate information to the public and decision-makers. The WHO Information Network for Epidemics (“EPI-WIN”) [3] is one strategy that provides resources and regular updates using a whole-of-society approach. Recognizing the importance of the community and promoting local knowledge and expertise to ensure guidance or public-health interventions are relevant, feasible, and appropriate.

The WHO EPI-WIN team wanted to facilitate the systematic sharing of local knowledge and expertise, capitalize on best-practice, and support decision-makers and community leaders to connect and share experiences to prepare and respond to high-impact health events. To understand the challenges faced by communities during COVID-19, community leaders, employers, youth groups, and the faith community were consulted for feedback. Key themes emerged that included the challenges of identifying and sharing trustworthy information and difficulties in facilitating co-development opportunities. The feedback also highlighted the willingness of communities to contribute and support others and the desire to share knowledge and expertise but also exposed broader topics relating to stress, mental well-being, and fatigue.

1.3. A Space for Communities to Connect and Share Best Practice – the Hive platform

These themes and feedback identified a need for a system to support communities, build partnerships and promote local knowledge and expertise. In addition, a framework was needed to foster connection, co-creation, and provide mutual support. The Hive platform

is designed to leverage current technology to complement the EPI-WIN approach and enhance the way that WHO supports and learns from communities [4].

The Hive platform aims to bring together communities, WHO, and other cross-disciplinary partners to co-create, co-develop, share knowledge, and to build from the foundations of community best-practice and lessons learned. Functionality has been included for community managers to self-manage and personalize their community space and to enable users to suggest local trustworthy sources of information. A continuous testing and validation cycle are critical to ensure development remains purposeful, appropriate, and aligned with community needs. The strategic direction of the Hive has been guided by user testing, and ongoing feedback will continue to contribute to the refinement of the product and strategies to support community engagement and collaboration at a much broader level.

2. Methods

2.1. The Hive Platform as a System

To deliver on the vision of ensuring that all people everywhere have access to the right information, at the right time and in the right format, the platform provides access to credible and trustworthy information. Given the complex nature of the current information ecosystem, and how individuals seek, engage and share information, the Hive is developed as a system to leverage the power of communities and the opportunities to be gained from community participation. Moreover, the data gathered from its feedback loops will guide the Machine Learning (ML) functionality of the Hive, presenting personalized and appropriate information, relevant to the interests of the individual. We envision the Hive platform enabling an inclusive response to public health events through multisectoral, multi-level communication and collaboration. The Hive will place the community and the community's information needs at the center and provide the tools necessary for knowledge exchange and co-creation.

2.2. The Technology Behind the Hive – A Process of Evolution and Refinement

The Hive system uses a continuously improving data acquisition system that gathers information from a defined list of global sources. The data acquisition service feature gathers the information from external sources, such as mainstream news outlets, and health authority websites, using web crawling and scraping. The process is triggered regularly to ensure up-to-date information on the Hive platform. After crawling and scraping the information, the content and metadata are stored and accessed by the indexer for enrichment and indexing. The system then tags each content and transforms texts into numerical values for ML. Hive's summarization feature uses a transformer model in natural language processing to learn contextual relationships between words in a document.

3. Results

This ML technique is then able to summarize the text. Categorization algorithms assign a pre-determined category to each content that will be able to further guide ML models to produce personalized and appropriate information relevant to the interests of the individual. These multistep processes are depicted in Figure 1.

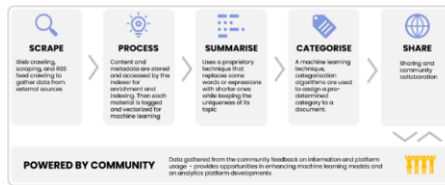


Figure 1: Data acquisition and data processing features of the

4. Discussion

4.1. Identifying & Verifying Trustworthy Sources of Information

The Hive uses three main pathways to gather information from online content and electronic media: 1) web crawling and scraping 2) community uploaded resources organized into collections 3) Suggested sources from community members identified as reliable that can be added to the platform. The continued development and refinement of functionality to facilitate community feedback on the quality and validity of information is key to achieving our goal of trustworthy information, powered by communities.

5. Conclusion

The HIVE is an ambitious, future-facing platform designed to transform the ways of working with communities before, during and after public health emergencies. It is an innovation that will support developing and maintaining community trust, enabling active community collaboration to address questions and concerns and the sharing of trustworthy and relevant information. In future work, the aim is to continuously improve community collaboration on the HIVE and utilize the latest information technology advancements, including data analytics and ML to expand the role of the community in high-impact public health events and complement Epidemic and Pandemic Preparedness and Prevention.

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