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Opinion

# The role of epidemiologists in communicating SARS-CoV-2 evidence: a call for adopting standards

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#### Key Messages

- Epidemiologists have a key role to play in conducting research to promote uptake of vaccination and other protective personal and social behaviors to combat SARS-CoV-2.
- It is important that evidence from epidemiological research on COVID-19 be easily accessible to the public and to policy-makers, and that any gaps in public understanding in this regard are identified and addressed.
- Towards that end, epidemiologists should communicate epidemiological terms, concepts, research findings and recommendations in clear, transparent and actionable terms so that the public can understand and apply the information to guide their behavioral choices in response to the SARS-CoV-2 pandemic.

## Introduction

By mid-April 2021, the novel coronavirus SARS-CoV-2 had infected an estimated 141 million people worldwide and had killed over 3 million, with a disproportionate number of deaths occurring among those with limited access to highquality health care, education and other important community resources.<sup>1</sup> Whereas scientific understanding of the SARS-CoV-2 virus continues to accrue, one known fact is that the transmission of SARS-CoV-2 depends on human behaviour. Experts agree that successfully quelling this pandemic will require broad and sustained adoption of both protective personal and protective social behaviours (e.g. social distancing, mask wearing, hand washing) and high vaccine uptake as recommended by public health authorities.<sup>2</sup> Collectively, these represent ambitious public health goals that will require an unprecedented degree of cooperation from both individuals and communities, cooperation that will depend in large part upon informed decision making and willingness to practise protective behaviours including undergoing vaccination.

Epidemiologists have an important role to play in achieving these public health goals as they are experts in conducting research on the determinants of health and health inequities, on the patterns and spread of disease within populations and on the evaluation of health interventions.<sup>3</sup> For example, well-designed and well-executed studies assessing the prevalence and incidence of the virus are vitally important for guiding health policies and vaccination priorities and recommendations. Similarly, population-based evaluations of the impact of immunization and the adoption of protective personal and social behaviours on infection and mortality rates are needed to inform the public and policy makers and to improve public health initiatives.

### Our call

In the current context, however, epidemiologists' work cannot be viewed as finished once such studies have been completed. Evidence from epidemiological research needs to be easily accessible to the public and policy makers, and gaps in public understanding need to be identified and addressed; limitations in evidence and in the public's understanding of such evidence impede effective COVID-19 prevention and control. Epidemiologists should be not only competent researchers but also trusted and transparent communicators of their research findings to policy makers, health care professionals, journalists and the public. Towards this end, we call for epidemiologists to communicate epidemiological terms, concepts, research findings and recommendations clearly, transparently and actionably so that the public can understand and apply the information to guide their behavioural choices and actions in regard to the SARS-CoV-2 pandemic. In this way, epidemiologists can help empower individuals to protect themselves, their loved ones and their communities from COVID-19, and also promote greater health equity across communities. For these very reasons we maintain that epidemiologists have an urgent ethical imperative to adopt epidemiological literacy standards. Failure to do so can hinder effective COVID-19 prevention and control. Specifically, and on behalf of the International Network

for Epidemiology in Policy (INEP), a global consortium of 24 epidemiological societies [https://www.epidemiologyin policy.org/] that advocates for integrity and equity in translational epidemiological research and practice, we call for epidemiologists to promote epidemiological literacy within society at large.

## Scope of the problem

Both individual and community willingness to practise protective behaviours during infectious disease outbreaks are negatively affected by a variety of factors. Prominent among these are concerns regarding the efficacy and safety of vaccines and other interventions and scepticism as to whether fair and equal access to such interventions will be guaranteed.<sup>4,5</sup> Significantly, even before the onset of the SARS-CoV-2 pandemic, vaccine hesitancy had been recognized as one of the top 10 threats to public health globally.<sup>2</sup> In the context of COVID-19, these concerns have been exacerbated by the spread of misinformation via social media as well as by the contradictory and/or complex nature of official messages (e.g. from government agencies and reputable scientific experts) concerning the virulence and transmissibility of the SARS-CoV-2 virus, the efficacy of vaccines and potential treatment options and the value of protective personal and social behaviours.<sup>6</sup> Moreover, the aggressive vaccine development time lines have raised doubts not only within the scientific community but also among members of the public at large regarding the quality of the evidence for the safety and efficacy of these new COVID-19 vaccines.<sup>7</sup> Misunderstandings regarding the design and interpretation of epidemiological research may further contribute to the public's refusal to exercise protective behaviours.8

The World Health Organization (WHO), in an effort to describe this situation, has coined the term 'infodemic', i.e., a condition in which an overabundance of information, including both misinformation and disinformation, is being disseminated in real time via multiple channels alongside the unfolding pandemic.<sup>2</sup> This infodemic poses the risk of eroding public trust in health care professionals, vaccine products and the value of behavioural efforts at both individual and community levels to mitigate the pandemic. As has been seen in previous vaccine campaigns (e.g. measles, polio), misinformation can significantly damage public trust in regard to vaccination and engender hesitancy in regard to vaccine uptake.9,10 Indeed, recent research shows that vaccine hesitancy-both in general, and in regard to COVID-19 in particular-is a growing phenomenon worldwide,<sup>11</sup> although this may change depending on the course of the pandemic. Similarly, many individuals have been careful to practice protective

personal and social behaviours, but their resolve may falter as the pandemic continues into its second year. Additionally, many others have not been as vigilant or have disregarded the call to adopt protective behaviours altogether.<sup>12</sup>

As a direct result of the pandemic and the ensuing infodemic, an array of epidemiological concepts and terms have been widely injected into the public discourse, terms that may be unfamiliar to, or poorly understood by, the average adult.

Gaps in understanding may be especially pronounced for individuals who struggle with what has been termed 'health literacy'. Health literacy is a multidimensional concept defined as 'the ability of individuals to understand and use information in ways which promote and maintain good health'.<sup>13</sup> One dimension, functional health literacy, refers to an individual's ability to both understand and apply health-related information in the context of a health care encounter. A second and complementary dimension, critical health literacy, refers to an individual's ability to evaluate and critically appraise information and information sources.<sup>14</sup> The latter has been shown to be even more important than functional health literacy in instances where individuals are exposed to contradictory health information.<sup>15</sup> Collectively inadequate health literacy, both functional and critical, has been identified as a significant health issue globally. Efforts to address it, including providing universal access to accurate and actionable health information and supporting lifelong learning of skills for achieving and maintaining good health, have been recognized as key to empowering patients and improving population health outcomes.<sup>16</sup>

## What needs to be done to tackle the problem? – Defining and enhancing epidemiological literacy

We call for enhancing epidemiological literacy in society at large. We define epidemiological literacy as the ability to gain access to, understand, appraise and apply epidemiological information in ways that promote good health. Advancing epidemiological literacy can have a 3-fold effect. It can: first, enable all key stakeholders, including epidemiologists, policy makers and individual members of society, to be more effective in mutual information exchange, critical appraisal of health data and knowledge adoption; second, help empower individuals and communities to make informed health decisions; and third, assist epidemiologists in building meaningful community collaborations to design studies that are relevant to local needs and to develop policy proposals that are grounded in an in-depth knowledge of local communities and their unique concerns, challenges and opportunities. Collectively, all three elements are needed if we together, as a society, are to successfully address the SARS-CoV-2 pandemic.<sup>17</sup> Our recommendations to advance epidemiological literacy standards follow.

## Recommendation 1: Define epidemiological concepts and terms in plain language

As a foundation for building epidemiological literacy, epidemiologists should define epidemiological concepts and terms in plain language and seek to communicate research protocols and results in a transparent, understandable and actionable manner. This recommendation is in direct response to the way COVID-19-related epidemiological parameters have been reported to date in the news media. For example, the 95% effectiveness of one vaccine product has been conveyed in the news media as meaning (incorrectly) that it protects 95 out of 100 vaccinees from COVID-19.<sup>18</sup> The correct interpretation is to express it in the form of a relative risk reduction, i.e. 'whatever your risk was before, it is reduced by [95]% if you get vaccinated'.<sup>19</sup> 'Herd immunity', another widely reported term, has been used variously to refer to: (i) the proportion of immune individuals in a given population; (ii) a particular threshold proportion of immune individuals that, if reached, should precipitate a decline in the incidence of infection; and (iii) a pattern of immunity that should shield a population from a wave of contagion due to a new infection.<sup>20</sup> As a result, the use of this term, in the absence of any further clarification, could confuse members of the intended audience(s), scientific and lay alike, create misleading expectations regarding the vaccine and vitiate the public's willingness to continue adhering to protective measures even if vaccinated.<sup>21</sup>

Efforts to advance epidemiological literacy are consistent with initiatives in Canada, the European Union (EU) and the USA to improve the accessibility and understandability of research about medicinal products to the general public.<sup>22</sup> From a global perspective, the Working Group XI of the Council for International Organizations of Medical Sciences (CIOMS) has urged that communication about COVID-19-related research be jointly developed with patient partners, and that such communication be 'timely, reliable and factual' and equally importantly, be 'disseminated in plain language'.<sup>23</sup>

To achieve this, we as epidemiologists must enhance our competencies as skilled communicators and learn from collaboration with health education and media communications experts. A number of plain language glossaries for public health and health care terms and concepts are available as resources in this regard, and several related initiatives have also been launched relevant to the SARS-CoV-2 pandemic itself. For example, the US Centers for Disease Control and Prevention (CDC) has a publicly available plain language glossary, and the Science in Media Center in the UK has a dedicated initiative to compile plain language terms pertinent to COVID-19.<sup>24,25</sup> We suggest that concepts and terms particularly important for epidemiological literacy should be defined. This would involve a two-step process: (i) gaining consensus among scientific experts on the technical definitions of these key terms; and (ii) translating these scientific definitions into plain language versions. The latter step would require applying plain language best practices. These practices include adhering to health literacy and numeracy principles, collaborating with representatives from patient, caregiver and health care professional communities in this process, addressing cultural context and choosing dissemination channels that are tailored to the preferences of the target audiences.26

## Recommendation 2: Disseminate research protocols and findings in plain language summaries

Similar to the EU Clinical Trials Regulation (EU CTR) 536/2014, which requires that product sponsors prepare and submit a plain language summary of the results of clinical trials, epidemiologists should prepare and disseminate plain language summaries of epidemiological studies, summaries that are developed based on input from the individuals and communities upon whom the research was conducted.<sup>22</sup> Journal editors should require the inclusion of a plain language summary as part of the manuscript submission process. A plain language summary should explain the key study findings, their practical implications for affected individuals and communities, and their relevance to public health policy.

In developing these plain language summaries, the focus should be on clearly communicating research findings to study participants and to the public at large as well as to journalists and policy makers. As part of this, efforts should be made to employ innovative communication methods, such as the use of personal stories, narratives, infographics, videos, cartoons and other forms of animation, and to leverage a range of different social, news and scientific media venues in doing so.

Guidances for plain language summaries has been established, including those authored by the Cochrane Collaboration and the American Institutes of Research.<sup>27,28</sup> Developing resources specifically for presenting epidemiological findings in plain language summaries would be a valuable and complementary addition to these existing resources.

## Recommendation 3: Establish new competency requirements in risk communication

In the longer term, we call for new requirements for competency in epidemiological communication, in terms of both practice and research investigating communication impact. As part of this, training should emphasize working in multidisciplinary teams consisting of representatives from the general public, health care, public health, health communication, pharmaco-epidemiology and the clinical, social and behavioural sciences. Epidemiologists should become familiar with applying frameworks, principles, strategies and tactics from both design science and implementation science. We also recommend using design science, which incorporates user-centred approaches that allow for repeated user input and design adjustments, to guide the development and evaluation of communication messages, including written vaccine communications.<sup>29</sup> Social marketing techniques, a key strategy used in implementation science to increase and sustain uptake of public health interventions, can be used to guide population segmentation into specific subgroups for the purposes of tailoring message content, format and the selection of communication modalities and dissemination strategies.<sup>30</sup> To further advance the science in this area, epidemiologists should be conversant with social environmental and behavioural change frameworks to guide the design, conduct and evaluation of such communication research, and they should be trained to use a broad array of data sources, data types and analytical methods, including mixed methods research designs.

Last, we recommend the establishment of a new discipline within the field of health risk communication, one that includes researching medicinal product risk communication interventions as additional determinants of health.<sup>31</sup> Efforts to establish such a discipline are already under way as evidenced by a series of recent dedicated conference and training offerings.<sup>32–35</sup>

## Conclusions

As we enter the second year of the SARS-CoV-2 pandemic, we are at a tipping point in which individual and community behaviours will play an increasingly critical role in determining whether the number of infections and deaths accelerates or declines.

To help address this, we must strive to ensure that all people, regardless of their health literacy and scientific sophistication, are epidemiologically literate. In doing so, we can help overcome inequities in health care access and enable individuals and communities to engage in informed decision making regarding appropriate health behaviours that advance their health and well-being. Heightened levels of epidemiological literacy can reduce the likelihood that people will succumb to misinformation regarding the SARS-CoV-2 virus and can serve as a prophylaxis against misinformation in future pandemic situations as well. We have proposed three recommendations that can, collectively, equip us as epidemiologists to more effectively assist in defeating this pandemic, recommendations that will also enable the field of epidemiology to remain 'fit for purpose' in the face of ever-evolving public health priorities in the longer term.

We recognize that whereas advancing epidemiological literacy is an important step, it will not be sufficient alone in overcoming vaccine hesitancy and resistance to protective personal and social behaviours. A host of other factors, including mistrust of the medical community coupled with long-standing inequities in access to and quality of health care, also play an important role in this regard. Many of these factors are structural and systemic in nature and thus require longer-term solutions. However, adopting epidemiological literacy standards as a core competency for epidemiological practice is an important step towards empowering individuals, communities and policy makers to address these systemic issues. Not least, promoting epidemiological literacy is one important action that all epidemiologists can undertake now to aid in the effort to defeat this pandemic.

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