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Lessons from the past

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WHO HEALTH EVIDENCE NETWORK SYNTHESIS REPORT 77

What are the historical roots of the COVID-19 infodemic? Lessons from the past

Nancy Tomes | Manon Parry





European Region

The Health Evidence Network

The Health Evidence Network (HEN) is an information service for public health decision-makers in the WHO European Region, in action since 2003 and initiated and coordinated by the WHO Regional Office for Europe under the umbrella of the WHO European Health Information Initiative (a multipartner network coordinating all health information activities in the WHO European Region).

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WHO Health Evidence Network synthesis report 77 What are the historical roots of the COVID-19 infodemic? Lessons from the past

Nancy Tomes | Manon Parry





European Region

Abstract

This scoping review explores the history of the term infodemic and its usefulness as a tool for public health policymaking. It presents the information-related problems the term has encompassed; historical research on these problems, which predate the term itself; and in-depth analyses of their iterations in three historical outbreaks with long-term significance for public health policy: the 1918 influenza pandemic, the beginning of the HIV/AIDS pandemic in the 1980s, and the 2003 outbreak of severe acute respiratory syndrome. Particular attention is paid to the characteristics of scientific practice that inadvertently contributed to the generation of misinformation, as well as other factors that played a role: historical legacies, persistent inequalities and a growing distrust of scientific authority. Historical perspective helps balance contemporary analyses of infodemics that focus too narrowly on the role of new social media in disseminating misinformation and disinformation. Insights derived from the historical record can also be useful to contemporary infodemic management.

Keywords

HEALTH INFORMATION MANAGEMENT, HEALTH COMMUNICATION, DISEASE OUTBREAKS, PANDEMICS, HISTORY OF MEDICINE

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ABBREVIATIONS

COVID-19	coronavirus disease of 2019
SARS	severe acute respiratory syndrome
SARS CoV	SARS-associated coronavirus

SARS-CoV-2 severe acute respiratory syndrome coronavirus 2

SUMMARY

The issue

In early 2020 WHO adopted the term infodemic to refer to problems created by the rapid circulation of information, misinformation and disinformation about severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; causing COVID-19). Since then, interdisciplinary research into the causal factors and dynamics of infodemics has greatly increased. One common assumption of that research has been the close association of infodemics with expanding digital access and the more-interactive communication platforms, including social media, available since the 2000s. This report demonstrates that information-related problems also occurred in outbreaks of infectious disease prior to the internet. Consequently, policy approaches that exclusively focus on recent changes in information technologies may need to be re-evaluated.

The synthesis question

What are the historical roots of the modern-day infodemic and what conclusions can be drawn from examining how information, misinformation and disinformation were spread and managed during previous disease outbreaks?

Types of evidence

An initial broad search of scientific, grey and popular literature published up to 2019 was conducted to determine the prevailing uses of the term infodemic and the challenges it represents, and to inform the search terms and inclusion criteria for the next steps in the search strategy. A systematic, structured search of academic literature was then undertaken to identify further articles on infodemics; of the 284 citations screened, 48 were deemed relevant and were closely analysed. Most results were in English, with one in Spanish and seven in Portuguese. The findings of the structured search informed the selection of three historical cases that became the focus of the next iteration of the search strategy; these searches yielded a further 120 articles, giving a total of 168 articles to inform the scoping review.

Results

The structured search revealed multiple, interrelated factors that contribute to the creation of infodemics, as well as factors that mitigate their complexity and impact: high levels of public confidence in health experts and government leaders; a diverse media landscape conveying that information is not being withheld or censored; coalescence between national policy and international scientific consensus; acknowledgement of the limitations of scientific knowledge as it is evolving; acknowledgement of the role of politics, values and priorities in public health policy; and the active participation of affected groups in developing and exchanging information.

The review of the historical cases – the 1918 influenza pandemic, the beginning of the HIV/AIDS pandemic in the 1980s, and the 2003 severe acute respiratory syndrome (SARS) outbreak – showed that all three exhibited information-related problems, including difficulties with the volume, veracity and variety of information available, as well as information voids created by lack of knowledge or suppression of information. The increasing diversification of media platforms exacerbated these issues by massively expanding the potential reach of misinformation and disinformation. Other factors also played important roles, including individual and public memory of historical circumstances and events, ongoing inequalities, and a broadening gap between claims made for the scientific management of new disease outbreaks and the more complicated reality of developing and applying new knowledge amidst competing economic, political and ethical priorities.

The historical analyses suggest that infodemics flourish in the expectation gap between an idealized faith in science and the hard realities of what science can produce at short notice. Over the last 50 years, these expectation gaps have widened due to changes in how science is done, how science is presented and perceived, how scientific communication occurs both among experts and with the public, how that communication is amplified by new information technologies and competitive media outlets, and how citizens in general are expected to understand and act on expert guidance. As a result, infodemics have become more complex and more intense in their impacts.

The findings indicate that infodemic management during disease outbreaks requires not just new forms of social media surveillance and management but also broader

strategies designed to account for inevitable uncertainties around the production and consumption of information about a new pathogen. Such uncertainties need to be addressed both online and offline across three linked domains: the scientific and expert community, the mass media, and the public.

Policy considerations

Based on this review's findings, the main policy considerations for mitigating the risks and impacts of infodemics are to:

- ensure that policy measures aimed at mitigating infodemic risks anticipate and address broad societal concerns related to the role of experts, trust in authorities and other issues that are difficult to address through technocratic solutions;
- engage with diverse media sources (including television, print and social media) to disseminate information to wide audiences and ensure that information is not being withheld or censored;
- nurture grassroots and local interactions to disseminate accurate information about disease outbreaks and public health measures by collaborating with civil society and ensuring that affected groups actively participate in information development and exchange;
- implement measures to improve public health literacy and increase awareness of the factors that inform how scientific knowledge is translated into public health guidance during a public health emergency;
- adopt prebunking techniques,¹ informed by historical analyses of the forms of misinformation that have been prevalent and recurrent across past disease outbreaks, in order to counter areas of historically grounded mistrust and misunderstanding;
- acknowledge scientific knowledge gaps, the potential for information to change and the limitations of fast-tracking the dissemination of research findings in order to limit public concerns relating to inconsistency in expert messaging and avoid undermining the credibility of and trust in scientific information as new evidence emerges in ongoing disease outbreaks;

^{1.} Prebunking techniques aim to debunk false or misleading information before it begins circulating.

- consider the historical legacies, as well as the social and cultural factors, that shape public attitudes towards and levels of trust in information channels when determining who is best placed to disseminate health messages in specific contexts (for example, public health authorities, government officials, civil society representatives or other actors); and
- promote or restore public confidence in government leaders, public health experts and organizations before emergencies occur.

1. INTRODUCTION

1.1 Background

1.1.1 Origins and significance of the term infodemic

WHO defines an infodemic as "too much information, including false or misleading information, in digital and physical environments during a disease outbreak" (1). (See Box 1 for definitions of key terms used in this report.) According to the WHO Regional Office for Europe, the coronavirus disease of 2019 (COVID-19) pandemic "has seen both reliable evidence-based information and rumours, conspiracy theories, and misinformation and disinformation circulating with unprecedented volume, variety, and speed" (2). The current pandemic illustrates the three Vs that data scientists use to describe an overabundance of information: volume (there is too much of it), velocity (it changes and spreads rapidly) and variety (it appears in many formats and platforms). Mechanisms such as peer review have also been weakened so that the results of scientific studies can be shared more quickly, thereby increasing the probability that they will have to be revised. Incorrect or incomplete information shared with no intent to harm (misinformation) can then be circulated deliberately to advance a political agenda (disinformation). Misinformation and disinformation often develop in relation to information voids: that is, critical gaps in availability and awareness of evidence-based findings about a disease outbreak (2). Too much information, misinformation and disinformation can intensify or lengthen outbreaks by causing confusion about which measures people should take to protect their health and by undermining trust in health authorities (1). Improving infodemic management is, thus, a very high priority for WHO today (3).

The term infodemic, a word blend of information and epidemic, was first used during the 2003 severe acute respiratory syndrome (SARS) outbreak to describe the ways in which new information technologies complicated risk communication during that event (4). Since 2003, the widespread diffusion of smartphones and other personal technologies able to access the internet has increased the potential for infodemics. In 2020 4.28 billion people used their mobile devices to access the internet (5); combined with the continued influence of older print and electronic media, this new level of connectivity has created a challenging information landscape.

While previous outbreaks have produced rumours and conspiracy theories, the speed and complexity of today's information networks have accelerated their capacity

to undermine trust in public health expertise. As a result, the COVID-19 pandemic has prompted a broad re-examination of best practices in risk communication, risk management and community engagement (6,7).

Box 1. Definitions

Infodemic. Excess information, including false or misleading information, in digital and physical environments during an acute public health event.

Misinformation. Incorrect, misleading or misattributed information circulated without an underlying agenda or intent to harm.

Disinformation. Incorrect, misleading or misattributed information circulated with a specific, often political, agenda. This includes incorrect, misleading or misattributed information, as well as information that is true but artificially amplified, and the manipulation of individuals' information-seeking, sharing and consumption behaviours.

Information landscape. The existing communication and information systems in the area; the flows of communication, emotions and group interactions that infodemics exist within.

Information void(s). The gap(s) between a community's information needs and the publicly available, evidence-based communication, which emerge due to evolving information needs, questions and concerns among the public.

Infodemic management. The systematic use of risk- and evidence-based analyses and approaches to prepare for and manage an infodemic in order to reduce its impact on public health. This includes ongoing surveillance and preparedness, such as following infodemic-focused parts of health emergency preparedness and response plans.

Source: WHO Regional Office for Europe & European Union, 2022 (2).

1.1.2 The value of historical perspective

As use of the infodemic metaphor proliferates in both professional and public spheres, its application warrants critical reflection and caution (7). On the one hand, early adoption of the term during the COVID-19 pandemic allowed WHO "to bring together a broad coalition of actors to take up medical mis- and disinformation as a serious issue and search for countermeasures and solutions" (7). On the other

hand, it has been used very loosely to cover a multitude of phenomena and has significant blind spots, such as a lack of historical depth in discussions of information-related problems. This report aims to contribute to a better understanding of these information-related problems by using a longer-term historical perspective.

Infodemics are often assumed to be a product of the internet era (8), yet their core components – overabundance of information, rapid spread of mis- and disinformation, information voids – are in fact not new (9,10). Focusing too exclusively on the social-media origins of contemporary infodemics obscures the longer-term dynamics of knowledge production and sharing that underlie them. New methods of scientific enquiry have long been accompanied by concerns over the quantity and quality of the information they produce (11–15). Indeed, the phenomenon of information overload dates back to Johannes Gutenberg's invention of the printing press (16). Nevertheless, in policy discussions that long perspective is missing: infodemics are represented as having "a short history [and] a long future" (17).

Without appreciating the longer-term dynamics underlying infodemics, policy responses may prioritize narrowly technocratic solutions over much broader approaches related to expertise, authority and trust. A better understanding of how infodemics have manifested over time and what methods worked to mitigate them in the past can help improve policy-making in the future. Looking at information flow in previous disease outbreaks can help to clarify what is new about COVID-19 – and what is not.

1.1.3 Objectives of the report

This scoping review provides a deep historical perspective on contemporary infodemics through a structured review of the information-related problems the term has encompassed; historical research on these problems, which predate the term itself; and in-depth analyses of their iterations in three historical outbreaks with long-term significance to public health policy: the 1918 influenza pandemic, the beginning of the HIV/AIDS pandemic in the 1980s, and the 2003 SARS outbreak. Each historical case involved a novel pathogen that spread quickly to multiple parts of the world. Each also prompted extensive information sharing among multiple stakeholders (scientists, public health officials, government leaders, media professionals and the public) as part of the overall effort to contain and mitigate the outbreak.

In comparing these cases, this review used critical perspectives from the history of knowledge (18) and from science and technology studies (19), which interpret

science and technology as socially and culturally constructed and context specific. As applied to the concept of an infodemic, this approach focuses attention on the social construction of information and information-based practices and how they have changed over time. What constituted "good" or "bad" information was not intrinsically evident: these distinctions reflected specific ideas, practices and contexts, and different stakeholders did not necessarily agree on what constituted important or reliable information or what actions it justified.

With these critical perspectives in mind, this scoping review examines the history of information sharing during a particular type of acute public health emergency: disease outbreaks. By combining a broad overview of information-related issues with in-depth analyses of three historical cases, the scoping review examines the extent to which the quantity and quality of information available during each outbreak became defined as a problem impeding its management. Comparison across time demonstrates how changes associated with new information technologies and mass media (primarily, print media in 1918; print and electronic media in the 1980s; and print, electronic and digital media in 2003) intersected with changes in scientific knowledge-making, public health communication and public participation in health policy-making.

This scoping review focuses primarily on the production and dissemination of information rather than its reception (the latter topic is so large and complex that it necessitates its own report). It uses the historical record to examine the real-time challenges of communicating about a novel pathogen during the height of an outbreak, that is, a so-called hot crisis (20). Such an in-the-moment perspective helps to identify unmet expectations for certainty and consensus that contribute to a sense of information overload and miscommunication. This approach highlights the characteristics of scientific enquiry, including the reliance on extensive debate and the questioning of evidence that may slow the development of consensus, and how the need to revise and update guidance in the light of new evidence can contribute to currents of both misinformation and disinformation.

Along these lines, the following four research questions helped to guide this scoping review.

- 1. How are infodemics related to scientific uncertainty about the pathogen and its threat level?
- 2. How are infodemics related to experts' difficulties in agreeing upon and carrying out containment and mitigation strategies?

- 3. How are infodemics related to the capacity of existing information technologies and media channels to quickly and clearly share expert guidance with the public?
- 4. How are infodemics related to the public's ability and willingness to understand, accept and act on the expert guidance conveyed via these media channels?

1.2 Methodology

This scoping review used a hermeneutic approach to assess relevant literature published up to 2019 (further details are given in Annex 1). The first step involved conducting a broad search of academic, grey and popular literature using the keywords "infodemic" and "infodem^{*}" to determine the prevailing uses of these terms and the challenges they represent (as discussed in section 1.1.1). The results of the broad search informed the development of the introduction, as well as the search terms and inclusion criteria for the next steps in the search strategy.

The second step involved a systematic, structured search of academic literature to identify how information, misinformation and disinformation have been spread and managed in past disease outbreaks. Of the 284 records identified, 48 fulfilled the criteria for inclusion after screening of titles/abstracts and subsequently of full texts; of these, 44 are directly cited in the review (21–64) and four are not (listed in Annex 2). The findings of this search are presented in section 2.1.

The third step involved iterative searches to identify relevant texts on three historical cases that provide a contextualized understanding of how infodemics have been managed in specific outbreaks: the influenza pandemic of 1918, the beginning of the HIV/AIDS pandemic in the 1980s, and the SARS outbreak of 2003. These were selected for comparison based on their predominance in the literature, historical significance, and relevance to issues of information sharing and management. Searches yielded a further 120 records that fulfilled the criteria for inclusion; of these, 104 are directly cited in the review (10,65–167) and 16 are not (listed in Annex 2). The findings of these searches are presented in sections 2.2–2.4.

2. RESULTS

2.1 Infodemics: general findings

The 44 texts included in the structured search addressed a range of disease outbreaks: HIV/AIDS, cholera, Ebola, swine flu (influenza A(H1N1)), Asian flu (influenza A(H2N2)), avian flu (influenza A(H5N1)), the 1918 influenza commonly referred to as Spanish flu (influenza A(H1N1) likely of avian origin), measles, plague, SARS, smallpox, typhus, yellow fever and Zika (21–64). The diseases that were most frequently related to issues of information dissemination were HIV/AIDS (21–30), cholera (31–36), swine flu (37–44) and the 1918 influenza (31,45–51). The vast majority of articles focused on one specific disease outbreak; however, one article addressed influenza, plague, typhus and smallpox alongside cholera (31), and one addressed both cholera and yellow fever (32). Most results were in English, with one in Spanish (37) and seven in Portuguese (31–33,45–48).

References to problems with information across all texts were flagged and then organized into categories according to the implied or explicitly identified causes. The causative factors identified as having contributed to the creation of an infodemic included political context/timing (34,52), the characteristics of the disease (41), the degree of scientific understanding (53), historical legacies (21,43,54), official sanction (21), the activities of the media (22,55,56), and pre-existing patterns of public understanding of and trust in public health recommendations (38,43). Multiple factors were commonly involved, and the role of the media increased in significance as it amplified the effects of other factors.

The findings of the structured search, in line with the WHO definition of the key characteristics of an infodemic (1), are discussed in detail within the categories of abundance of information (section 2.1.1; evaluated as being proportionate or disproportionate to the risk to global public health) and quality of information (section 2.1.2; including public and professional perceptions of the quality or credibility of the source). Section 2.1.3 discusses the under-researched issue of the impact of information, which received limited attention in the literature identified in the structured search.

2.1.1 Abundance of information

The structured search showed that media coverage created an amplifying effect through a self-perpetuating cycle of increasing coverage during a disease outbreak (57). The diseases most commonly associated with high levels of media

attention were Ebola (55,58,59), avian flu (53,54) and Zika (56). Media coverage of Ebola and Zika were particularly sensational due to their severe symptoms of each and, in the case of Ebola, its exoticization as an African disease in Western media (55,56). The major factors driving media interest in avian flu included timing and recent historical precedent, as a 2005 outbreak among domestic birds followed closely on two other agricultural outbreaks that had a major impact on the food industry: bovine spongiform encephalopathy, and hand, foot and mouth disease (54). The 2009 swine flu pandemic also generated extensive media coverage. In the early period when little was known about the pathogen, press reporting of the rising rates emphasized the deadly threat but not the potential for an effective public response (41). More generally, journalists' limited ability to evaluate epidemiological bulletins or the health standards used to calculate risk led them to unintentionally overstate the danger (41).

The media industry's commercially driven tendency to exaggerate threats to attract readers often compounded this, but scientists also sometimes contributed to this style of reporting. For example, when potential H5N1 virus transmission from birds to humans was generating concern about avian flu, some scientists deliberately used historical references and frightening statistics to try to encourage action (54). These messages were echoed by members of the media, who drew provocative parallels between pandemics to increase the perceived relevance and impact of their reporting (54). Media interest also followed the publication of two articles in the journals *Nature* and *Science* that concluded that the circulating strain of the H5N1 virus and the influenza virus of 1918 shared structural similarities, as this association implied that the two viruses posed a comparable level of threat to life (53). The practice of linking current events to other well-known episodes can constitute and generate misinformation by eliding the differences between historical and contemporary contexts that significantly alter the level of danger of a given outbreak, such as the structure of health systems and the availability of treatments (41,54).

Importantly, although media outlets pick up on and reinforce trends in scientific publishing, these trends do not necessarily indicate rising importance of the issue or the degree of threat. In fact, an increase in scientific publications on a specific topic can be driven by research funding priorities, or seeded by scientists intending to influence the allocation of research funds (53).

Historically, in spite of waves of media sensationalism, the prevention of panic among the public has been a common goal of both government and media (43). However, underreporting of pandemics also contributes to infodemics in the short term by

creating an information vacuum that creates anxiety and drives rumours, as in the early years of HIV/AIDS in general (21–30) and the beginnings of SARS in 2003 in particular (60–64), and in the medium and longer terms by undermining public trust in authorities, who may be seen to have minimized a credible threat (43). The 1918 influenza pandemic and the beginning of the HIV/AIDS pandemic are associated with media attention that, at least prior to widespread local impact, sometimes a limited impact on specific communities or regions (21–24,31,45–51). During the early years of HIV/AIDS, community groups, especially gay men, began circulating information internationally to counteract growing fear as well as misinformation in mainstream media that filled the vacuum created by government inattention to or minimization of the threat (23,24).

As expected, given the difficulty of maintaining consensus among official sources of information and all media, including social media, dissensus was a common feature of news coverage of disease outbreaks. The degree to which the press critiqued governments during times of crisis was highly specific to the particular media culture of each country. During the 2009 swine flu pandemic, for example, Swedish media abandoned scrutiny of official policy, while Italian media presented diverging views, with endorsement or criticism according to the traditional political affiliations of media outlets (38). In the United Kingdom, in keeping with a tradition of watchdog journalism, media criticism of the government response was widely spread across different media outlets regardless of their usual political allegiance (38).

Although consistency in health communication is valuable for nurturing public trust, strong media consensus is unachievable given the potential for international information exchange in a globalized world. Moreover, the literature showed that such consensus can be counterproductive if the public becomes distrustful of a lack of diverse public debate. This occurred in Quebec during the 2009 swine flu pandemic and led some people to turn to social media and international news for alternative perspectives (43). Although in the short term the consensus between official and mass media information regarding the benefits of vaccines against the H1N1 virus was credited with high vaccination rates, in the longer term it may have undermined the credibility of health authorities "by giving the public the impression that they were manipulated and not given the appropriate information to make an informed choice" (43). As discussed in section 2.1.2, in regard to perceptions of the quality of information, such undermining of public confidence can contribute to infodemics years later.

2.1.2 Quality of information

Within these broader media landscapes, both who is providing information and how information is expressed contribute to infodemics, revealing the interplay of official sanction with pre-existing patterns of public understanding and trust. The literature reflected that health experts and government leaders figured most prominently in media reports, and were quoted much more frequently than, for example, members of the public affected by an outbreak (50). However, these prominent groups did not always share the same platforms. In Sweden during the 2009 swine flu pandemic, for example, health experts rather than government leaders provided official information to the media. Their focus on technical information, combined with public perception that they were outside politics and the consensus style of Swedish society, is credited for the lack of public dissent over health policy in this period (38).

Political context and timing also play an important role. For example, the goal of the Government of South Africa to separate medicine and politics by leaving official commentary to health professionals during the outbreak of cholera in 1980–1983 was discarded in the 2000–2003 outbreak in favour of additional commentary by government representatives. This strategy was better suited to the context of increasing democracy in the post-apartheid transition period, which allowed for a more open critique of health policy than had previously been possible (35). Instead of claiming that public health decisions were entirely separate from political concerns, leaders in this case acknowledged that medicine and politics both played a role in controlling the spread of the disease. Moreover, public health authorities may not always be perceived as neutral and objective (44); however, they may nonetheless be expected to be more singularly focused on a disease threat than government leaders, who may be assumed to be balancing competing priorities.

Evidence of the political power of pandemics and their use by governments to advance other agendas were repeatedly seen in the identified literature (34). Examples of the role of political context include the Government of the United Kingdom's mobilization of the 1961–1962 smallpox outbreak to limit migration from former colonies (52). As a result, separating out good-quality, reliable information from unreliable information is not as simple as distinguishing between official and unofficial sources.

In addition to withholding information, government members sometimes distributed inaccurate information. Public endorsements, even if later retracted, have contributed to the longevity of misinformation even after intensive official criticism, thereby

demonstrating the significant role of official sanction. For example, in Nigeria, the credibility of a rogue cure promoted as a curative vaccine for HIV by Nigerian physician and epidemiologist Jeremiah Abalaka was bolstered by conflicting state responses, including use by the military versus disavowal by the vice-president (21). Despite the vocal opposition of health professionals within the country, proponents were also able to claim international expert support for the treatment after the journal *Vaccine* published an article by its creator claiming, but not actually demonstrating, success (21).

Government and public health representatives have also struggled to keep pace with revelations first released in the media, creating information gaps for members of the public seeking the official reaction to breaking news (43). Unofficial sources have been crucial for disseminating reliable information in contexts where the official response has been silence, minimization of risk or scapegoating. This was a core feature of the dissemination of HIV/AIDS information, and has been largely deemed a success (24).

Attempts to mitigate mis- and disinformation can be hampered by a lack of faith in officials that runs far deeper than a contemporaneous distrust of individual figures or political parties. Examples of the influential role of historical events in fostering scepticism of authorities include the 2009 swine flu pandemic, when members of the public in France distrusted official statements on vaccine safety, apparently due to damaged confidence in the Government caused by state minimization of the health risks of the Chernobyl incident in 1986. This was exacerbated by media coverage of experts, including doctors, advising against vaccination (43).

2.1.3 Impact of information

The results of the structured search indicated that the wider impact of mis- and disinformation on individual behaviour, assumed in the media and in academic literature to be a major problem, has actually been under-researched. Although people may be familiar with specific myths (often through media reports that discount them), their attitudes and activities may be more influenced by other factors (25). This corresponds with the complex picture presented across the field of health communication, which amply documents the difficulty of influencing long-term behavioural change solely through the dissemination of information.

Assessing the impact of infodemic characteristics on the spread of disease is complicated. Limited reliable information can be detrimental, but an abundance of information still poses challenges for assessing what information is accurate

and of high quality. Moreover, an abundance of high-quality information from credible sources does not always translate into effective action at different levels of government or among the general public, as seen in the 1918 influenza pandemic when people in various parts of the United States of America failed to accurately recognize the threat (49), or in South Africa in the early 1980s when HIV/AIDS was assumed to pose no risk to the heterosexual population (22).

2.1.4 Main findings of the structured search

Problems with information dissemination reflect wider issues such as the distortion, amplification or rejection of information to advance political agendas or for other social, economic or cultural reasons. The structured search showed that, due to its association with marginalized groups and morally loaded topics such as sex, homosexuality, sex work and drug use, the beginning of the HIV/AIDS pandemic exemplified how biomedical, social, political, economic and cultural dimensions intersect to shape the course of an outbreak. However, as discussed in sections 2.2 and 2.4, these factors have also affected information management during other outbreaks, including of respiratory illnesses.

Throughout the structured search, a set of factors that mitigate the risks and impacts of an infodemic were either exemplified in particular cases or implied as countermeasures to what actually occurred: high levels of public confidence in health experts and government leaders (38); a diverse media landscape conveying that information is not being withheld or censored (43); coalescence between national policy and international scientific consensus (21); acknowledgement of the limitations of scientific knowledge as it is evolving (23,24); acknowledgement of the role of politics, values and priorities in public health policy (35,44); and the active participation of affected groups in developing and exchanging information (23,24).

Sections 2.2–2.4 present examples on how these factors influenced the dissemination of information during three different outbreaks: influenza, HIV/AIDS and SARS.

2.2 Findings on the influenza pandemic, 1918

2.2.1 Overview and context

The 1918 influenza pandemic was the first global outbreak to test the gains in public health science brought about by the advent of bacteriology (65). It also demonstrated the greater rapidity with which information could be shared across

great distances via the telegraph (66). Although it became widely known as the Spanish flu, it is unclear where the novel variant first emerged (10,49). Once seeded among troops serving in the First World War, the outbreak spread quickly in Europe, North America and South Asia, eventually reaching even remote parts of the world (65–84). Unlike seasonal influenza, which typically affected the very young and very old, this variant produced unusually high mortality rates among young adults. Estimated mortality rates range from as low as 17.5 million to as high as 100 million, with 50 million being a commonly used figure (85).

2.2.2 Expert understanding of the influenza pathogen

The 1918 pandemic occurred after a half-century of advances in laboratory and epidemiological methodologies that had helped to contain previously deadly diseases. However, these methods did not translate into confident or speedy responses (65). Using the same laboratory methods that had worked previously to isolate the causal microorganisms of infectious diseases, researchers could not agree on influenza's microbial agent, and efforts to come up with a vaccine also failed (86–88). Some experts argued that these failures suggested that the causal agent was not a bacterium but a virus, a class of microorganisms that by the 1910s was known to exist but was difficult to study (67). In 1933 that hunch proved correct when British scientists finally succeeded in isolating the influenza A virus (67), but in 1918 efforts to control the pandemic's spread had to proceed without knowledge of the specific causative microbe. Influenza had long had a reputation for being a puzzling disease that followed unpredictable patterns (10). Still, based on observation of its behaviour, public health authorities believed they knew enough to attempt to slow its spread (89).

2.2.3 Expert guidance on controlling the spread of influenza

Both experts and the public believed that influenza was a respiratory infection spread by a sick person sneezing, coughing and spitting, and that, once dried, these infective secretions could be mixed into dust and dirt (10,67). To slow its spread, public health officials relied on a toolkit of practices that predated the development of modern bacteriology, including quarantine, isolation of the sick and other forms of physical distancing, as well as disinfection and general cleanliness (10,67,68). They produced broadsheets and leaflets to explain the steps the public needed to take to stay safe, and relied on newspapers' willingness to reprint them to amplify these messages (67).

Unfortunately, the symptoms of influenza mimicked those of milder diseases; without a reliable diagnostic test to identify who had it, finding and isolating sick

people before they spread the illness to others was difficult **(68)**. As the number of cases quickly overwhelmed both home and hospital caregivers and increased the likelihood that others would be infected, public health officials began to limit people's movement by asking them to stay away from crowded places **(67,68,69)**. However, maintaining these measures led to serious economic and social disruptions that many people could ill afford, especially in wartime **(67)**. Given the speed of the outbreak's spread, formal quarantine procedures – the barring of population movements between or within countries – were also extremely difficult to implement, and wartime conditions further slowed public health responses **(67,69)**.

In choosing not to impose widespread closures, some public health leaders highlighted the danger of provoking fear or panic. In the United States, New York City's Health Commissioner said that in avoiding such closures, "[m]y aim was to prevent panic, hysteria, mental disturbance, and thus to protect the public from the condition of mind that in itself predisposes to physical ills" (66). Many feared that, if treated too harshly, people might try to flee and spread the disease in the process, or they might resist violently by burning hospitals or attacking people with influenza and their caregivers. Public health authorities also faced pressure from businesses to minimize economic disruptions (66).

2.2.4 The role of new information technologies and the media in amplifying information and misinformation about the influenza pandemic

By 1918, many countries had the media capacity to amplify fears of the influenza pandemic; wire services allowed daily newspapers to compete for readers by promising full, dramatic coverage of politics, business and other public issues (90). However, in Allied nations, wartime restrictions on news reporting appear to have toned down pandemic coverage (69). In Canada, the news blackout fed into dissatisfaction over how the pandemic had been managed by both military authorities and the new Union Government (69). In the United Kingdom, the Government exerted informal pressure to limit domestic coverage of the pandemic while allowing extensive reportage on it in other parts of the British Empire; that decision also led to distrust in and dissatisfaction with the pandemic policy (67). The United States exerted some censorship over news reported from the front lines, but made no systematic effort to control home-front coverage (70).

Despite the more competitive, commercialized news environment that had developed in many affected countries, the overall tone of pandemic reporting remained relatively restrained (10,65). Journalists' criticism of responses to the pandemic concentrated more on heartless landlords, inattentive physicians and fraudulent influenza treatments than on the failures of the public health system (10). Other than publishing readers' letters complaining about specific measures, mainstream print outlets offered limited options for the registration of dissenting views (68,71). Although conspiracy theories about the influenza's origin existed, they did not gain wide circulation in the mainstream press (10). In the Allied nations, Germany's scientists were rumoured to have invented not only chemical weapons but also forms of germ warfare, and an American military officer suggested that U-boats had brought the influenza to the United States (10). Similar claims were made in Italy (86). However, an extensive review of newspaper coverage in 1918 and 1919 showed that the idea of Germans conducting germ warfare did not gain widespread circulation in the press; when mentioned, it was often accompanied by ridicule (10).

2.2.5 Public responses to the influenza pandemic and to media coverage

Archival records show that the 1918 influenza pandemic generated fear and suffering in many communities (71,91), as well as questions about the decision-making of public health authorities (10,68). Despite this, overall newspaper coverage of the influenza did not appear to amplify fear, suffering and suspicion. Several explanations have been suggested for the low-key treatment of the pandemic. First. the wartime context influenced both the information shared and the response to it (10,65). Secondly, mainstream newspapers did not present particularly critical views of public health decision-making, beyond carrying the occasional critical editorial or letter to the editor (71). This lack of amplification, combined with the uneven implementation of public health measures, may help to explain the dearth of evidence on widespread violent resistance to influenza control measures in European countries, the British Empire and the United States (10,67). In the American city of San Francisco, mask mandates for the public provoked scattered, peaceful protests (72). However, in contrast to previous epidemics of cholera and bubonic plague, no evidence was found to suggest that the influenza pandemic produced riots or hospital burnings (10).

2.2.6 Overall findings and conclusions

In many respects, the 1918 influenza pandemic meets the criteria of an infodemic: there was an abundance of information and uncertainty about how to process it. However, compared with later pandemics, the media and its influence on the public did not emerge during or after the pandemic as explanations for why influenza was so hard to manage. Put another way, while there was indeed

widespread confusion over how best to contain the pandemic, that confusion was not attributed to having too much information about the pandemic. Instead, the press tended to reflect, rather than amplify, a general sense of uncertainty about how to manage a highly contagious outbreak in a mass society (66). A review of recent work confirmed the conclusion from 1989 that the "most difficult problem was organization, not publicity" (87).

2.3 Findings on the early HIV/AIDS pandemic, 1980s

2.3.1 Overview and context

In 1981 the first cases of a suspected new disease were reported in the US Centers for Disease Control's epidemiological bulletins (92). Emerging at a time of high scientific and political confidence that infectious disease could be effectively managed, the sudden appearance of a new, untreatable and fatal outbreak generated extensive and sensational media coverage (93). In the context of the new electronic media and computer technologies that emerged after the Second World War, mis- and disinformation circulated worldwide at unprecedented speed. At the same time, this media environment offered new opportunities for reaching mass audiences with public health messages, and for affected groups to exchange information and knowledge internationally.

2.3.2 Expert understandings of the HIV/AIDS pathogen

The early years of HIV/AIDS presented a significant knowledge gap, as researchers faced mounting cases of unusual illnesses such as Pneumocystis carinii pneumonia (a fungal lung infection) and Kaposi sarcoma among young, previously healthy individuals. As the clusters were first noticed among men who have sex with men, health professionals and the media began to use the term gay-related immune deficiency (94). This framing significantly limited the development of scientific knowledge, as well as of public health policy (95). Early cases among people who did not fit the profile were left out of epidemiological bulletins and diagnostic criteria, meaning that the emerging epidemic among Black Americans went unrecognized (96) and the diagnosis and treatment of women with HIV/AIDS were constrained (97). Scientists' emphasis on at-risk groups (known as the 4-H club: heroin users, people with haemophilia, Haitians and homosexuals), hampered an understanding of the routes of transmission and the heterosexual spread of HIV (98). The myth of patient zero, a Canadian airline steward blamed for introducing HIV

to the United States and infecting large numbers of men (99), drew on a flawed epidemiological study connecting clusters of cases (100).

Most of the early theories of the causes of AIDS focused on the idea that lifestyle factors, such as drug use, were weakening the immune system and allowing rare illnesses to flourish in affected patients (101). The virus that causes AIDS was identified by Luc Montagier at the Pasteur Institute in Paris, France, in 1983, and soon after by Robert Gallo at the National Cancer Institute in Bethesda, United States. The identification and subsequent confirmation of the virus were associated with a high-profile dispute over credit and diplomatic negotiations between the French and American governments, which were finally resolved in 1987 (102). This controversy, amidst ongoing debate about the possible role of additional factors, created room for the competing claims of other researchers, including cancer researcher Peter Duesberg at the University of California, Berkeley, United States, to continue to circulate in scientific publications, as well as in the mass media (101,103). Peter Duesberg has become the most prominent scientific figure in the global movement of AIDS denialists, who do not deny the existence of AIDS but dispute the idea that HIV is the (sole) cause and argue that AIDS drugs are toxic. Although his ideas have been increasingly marginalized within the scientific community, this marginalization enhanced his credibility as a dissident scientist and contributed to his appointment in 2000 to South Africa's Presidential Advisory Panel on HIV and AIDS.

In the mid-1980s, the predominant scientific theory that HIV originated on the African continent was heavily criticized by African physicians and politicians, who argued that alongside spurious claims about values and sexual behaviours driving the epidemic there, this was another example of racist science (104). Russian-born biophysicist Jacob Segal, a resident in East Berlin, Germany, instead blamed the United States military for creating and releasing HIV (105); this claim was promoted in Russian disinformation efforts that then spread through news media (106,107).

2.3.3 Expert guidance on controlling the spread of HIV/AIDS

Despite the relatively rapid isolation of the virus that causes AIDS in the mid-1980s, efforts to develop a preventive vaccine failed in the 1980s and 1990s (103), and have still not succeeded (108). In the early years of the pandemic, the main strategies used to slow and contain the virus's spread were testing and preventive health education. However, compounded by the knowledge gap discussed above, slow government responses across countries with distinctly different political contexts,

including China, India, the Russian Federation and the United States, increased the extent of information voids (109).

In China, where the first cases were reported in 1985, the Ministry of Health did not develop effective campaigns to educate and promote behavioural change among the general public until 1998 (110). In the meantime, nongovernmental groups focused on providing education and services (109). In India, where the first cases were reported in 1986, the criminalization of sex work, drug use and homosexuality undermined the official response, and elected politicians did not mention the topic of HIV publicly until 2001 (109,111). In the United Kingdom and the United States, homophobia and the association of HIV/AIDS with sexual permissiveness, marginalized groups and drug use hampered the development of accurate information and its dissemination to the public (112,113). Despite a slow start, Brazil became an international model of success for its development of a comprehensive response, which drew on extensive collaboration with civil society organizations to design policy and communications, including programmes to combat homophobia (114).

Mis- and disinformation played a major role in increasing the severity of the HIV/AIDS epidemic in South Africa (98,115). After the first reported cases in 1982, the public health response was slowed by a lack of commitment to the issue under the apartheid regime and a failure to appreciate the risk of heterosexual spread of HIV (109,116). The societal instability of the post-apartheid transition period further undermined the Government's response (22). From the late 1990s to 2008, active denialism under President Thabo Mbeki's Government delayed access to antiretroviral therapy, contributing to an estimated 300 000 preventable deaths (101,117,118).

As government-led education campaigns for the general public were politically fraught in many countries, the dissemination of more direct information often depended on civil society organizations, particularly in regions where the government response was weak, such as Ireland (23), South Africa (119), the United Kingdom (112), and the United States (113). Recognizing the major role of civil society groups in shaping and delivering public health efforts, WHO's Global HIV Programme made such collaboration a cornerstone of its work (120,121).

2.3.4 The role of information technologies and the media in amplifying information and misinformation about HIV/AIDS

News media played an active role in disseminating mis- and disinformation, most significantly regarding the representation of which groups were at risk (for

example, by excluding heterosexual women), the origin of the virus, and the routes of transmission between people and around the world. It is notable that medical conceptualizations have been central to much of this misinformation. For example, the term gay-related immune deficiency was altered in newspaper references to a gay plague (122). Sensational media coverage contributed to the stigmatization of the most-affected groups and fed back into HIV/AIDS policy-making by promoting the adoption of measures with limited or counterproductive public health impact but popular or political appeal, such as quarantines and travel bans (123,124). The myth of patient zero as the source of American AIDS (99) fuelled fear of people with HIV and led to attempts to criminalize HIV transmission and nondisclosure of positive status (100).

At the height of media sensationalism, claims circulated between partisan and more mainstream news outlets, demonstrating the interaction between active disinformation efforts and their inadvertent dissemination by different press sources. Between 1985 and 1987, for example, the speculation that HIV may have originated in a military laboratory in the United States began circulating in the American gay press, drawing on arguments by some American and British doctors who attributed an artificial origin to AIDS (105,125). Russian media circulated these claims, citing American news sources, which fuelled further coverage in the mainstream media, including the United Kingdom's *Sunday Express* (126). Academic research was also picked up and distorted in mass media reports that, reflecting their longstanding tendency to generalize and exoticize news from Africa, made racist claims about voracious and depraved sexual practices as drivers of the epidemic in that region (127).

Historical inequalities, past events and lingering prejudices provided fertile ground for misinformation. In South Africa, President Thabo Mbeki's Government's dissident approach to HIV/AIDS has been linked to distrust stemming from a history of colonial and apartheid inequality in general, and the vilification of traditional healers and healing practices in particular (104,118,128). Articles promoting the idea that HIV was manufactured in an American laboratory deployed wider scepticism of the African origin theory as racist (106,107), as well as memories of racial discrimination to enhance the credibility of these claims in post-colonial societies (106). The role of scientists in the genocide of the Holocaust was heavily referenced in Russian news on this topic (129).

However, media coverage of shifting expert knowledge and recommendations in the early years of HIV/AIDS often included commentary on conflicting interpretations

and the need for further research (93). Moreover, the circulation of dissident theories did not indicate the uncritical adoption of these ideas. As part of the international exchange of media information among people tracking developments in the AIDS pandemic, Ireland's *Out* magazine published American media interviews with Peter Duesberg in 1987 in which he continued to question whether HIV was the cause of AIDS. Although he suggested that safe sex practices may not be necessary if his theory was correct, the magazine encouraged readers to continue following the guidelines until knowledge on this was definitive (23). This reflected the uncertainty of the time, before the single-cause theory of HIV formally coalesced among the majority of AIDS researchers (103).

2.3.5 Public responses to the HIV/AIDS pandemic and to media coverage

A significant dimension shaping the adoption or dissemination of mis- or disinformation is the context of pre-existing beliefs and experiences that align with inaccurate or deliberately misleading information and serve to confirm its validity. The genocide theory has persisted in the United States, and has been linked to systemic health inequalities and ongoing distrust of the medical profession among marginalized groups, including Black, Hispanic and Asian/Pacific Islander men who have sex with men (130,131). The claim that HIV is the product of American military research has proliferated among communities who distrust the expertise of the United States Government (132). Researchers cite the collective memory of the long history of medical mistreatment (133–135) and the ongoing impact of racism on health and health care (117) as key factors fuelling such distrust.

The impact of infodemics on individual behaviour has been harder to assess, with research weakened by the uncritical acceptance of a presumed link between being exposed to misinformation and basing one's actions upon it (136). More robust studies investigating the complex relationship between attitudes and actions are often highly localized, but suggest that individuals can hold contradictory opinions simultaneously and that behaviour may be shaped more by personal circumstances and past experiences with health-care professionals, government agencies and international organizations than by particular examples of mis- or disinformation (25,127).

2.3.6 Overall findings and conclusions

The HIV/AIDS pandemic was the first global outbreak to combine intense media and public scrutiny of scientific and political responses with the mass mobilization

of civil society groups, which created challenges as well as opportunities for effective communication. The increasing diversity of media platforms enabled the rapid dissemination of mis- and disinformation – some of which was generated by scientists themselves – but also allowed for the circulation of critiques and correctives. Pre-existing animosities among experts, officials and particular target groups fuelled the politicization and moralization of public health advice and undermined the collaboration necessary to manage the infodemic in such a diffuse media environment.

2.4 Findings on the SARS outbreak, 2003

2.4.1 Overview and context

In 2003 the outbreak of SARS tested new pandemic preparedness planning that had been done in anticipation of novel biological threats (137). The first known case appeared in November 2003 in Fusan, a city in southern China; by the time the pathogen was isolated in February 2003, SARS had spread to other parts of the world along train and aeroplane routes (138–147). When WHO declared the outbreak to be contained in early July 2003, SARS cases had spread to 32 countries, causing over 8000 people to become ill and killing over 900, a case fatality rate of around 11% (138). Although a comparatively small outbreak, SARS attracted intense media scrutiny as an example of the new disease risks associated with globalization, and as "a warning to the world" of what a novel virus could do (138).

2.4.2 Expert understandings of the SARS pathogen

In the early phases of the SARS outbreak, physicians did not immediately recognize that the SARS agent was an unknown pathogen (138). As its speed of transmission and the severity of symptoms became apparent, some began to suspect that a novel virus might be its cause (138). Physicians and public health officials in affected cities were pressurized to downplay the extent and severity of the outbreak due to possible negative economic and political consequences (138,139,148). As a result, the exchange of expert information about the outbreak was initially limited (138,139,149).

As the outbreak spread further, public health officials in nearby countries heard rumours of its severity and became concerned (149,150). Researchers sought to obtain samples from affected patients and began to test for possible pathogens (149,150). An investigation of an outbreak of cases among travellers staying at the Metropole Hotel in Hong Kong SAR traced them back to one highly infectious individual, alerting experts to the possibility that some people with SARS could spread the

virus more easily than others (151–153). Eventually, scientists in Hong Kong Special Administrative Region isolated the novel virus responsible, which was officially named SARS-associated coronavirus (SARS CoV) in March 2003 (138,149). By that time, SARS had already spread to multiple countries (138).

2.4.3 Expert guidance on controlling the spread of SARS

During the short course of the SARS outbreak, no effort was made to develop a vaccine (108), and so preventing its spread and mitigating its harms relied on other public health measures. Delays in recognizing the extent and severity of SARS may have slowed the dissemination of awareness and information necessary to convince public health authorities to take these measures (139). The observation that the disease spread rapidly in hospital settings led to new guidance for health-care workers on the need to practise enhanced barrier protection such as gowning, masking and disinfection (138). To slow its spread outside hospitals, public health experts began to consider other measures, including quarantine, isolation, travel bans and physical distancing. Building public support for these measures required communicating the dangers of this novel pathogen (138).

In deciding what measures to adopt and publicize, public health authorities faced difficult choices: share information that might produce panic behaviours, or suppress it and allow even more dangerous rumours to emerge (151). In some places, fear of a government-imposed travel ban prompted people to flee affected areas, thereby spreading the virus (140). Lockdowns imposed on hospitals and housing complexes intensified public fears about both the outbreak and how it was being managed (141). Eventually, traditional measures to manage contagious diseases, including quarantine, travel bans and physical distancing, seemed to contain the outbreak. However, as their rollout was inconsistent over time and place, assessing which ones worked most effectively to control the outbreak was difficult (154).

2.4.4 Role of information technologies and the mass media in amplifying information and misinformation about SARS

Electronic modes of sharing information via email and websites figured importantly in the global response to SARS. By 2003, public health workers had computers, laptops and cell phones to access and share data (155). Indeed, WHO officials were first alerted about the outbreak and its severity via email (138). In an editorial entitled "SARS, the Internet and the Journal", the *New England Journal of Medicine* noted how important email and web platforms had been to information sharing about the outbreak, including its own coverage (156). Citizens also made use of new electronic technologies. By the early 2000s, China had the most mobile phone subscribers of any nation in the world (157). In the early stages of the outbreak, residents used cell phones to send text messages sharing information about its spread that had not been released by public officials (138). However, this unvetted communication also caused problems. In Hong Kong Special Administrative Region, an April Fool's Day prank by a 14-year-old who posted a false message on a local newspaper's website that the city was about to be declared "an infected port" led to panic buying in the city's stores (141). In the aftermath, local information technology engineers created a website to post reliable information about the outbreak (141).

Older forms of media also played critical roles in information sharing during the SARS outbreak in Asia (138). In affected areas, local newspapers' early reports on the "mystery disease" alerted residents to the outbreak (138,141). They also alerted public health agencies, which routinely monitor the press for reports about unusual events, that an outbreak might be under way (138).

During the SARS outbreak in Toronto, Canada, information sharing also involved a mix of both old and new media forms. For example, members of the Ontario SARS Scientific Advisory Committee relied on emails, laptops and cell phones to share data and coordinate actions with one another and WHO, while at the same time monitoring local and Chinese newspapers to fill information gaps (155). To keep the city informed, the Toronto public health authorities set up a SARS hotline and held daily press briefings. However, with multiple television stations and newspapers competing for a good story, managing "the voracious appetite of the media for information" was difficult (158). Calming reports from one leader seemed to contradict more concerned messages from another, creating suspicion of a possible cover-up (155). Traditional media outlets such as newspapers and television news broadcasts played a larger role in amplifying such concerns compared with digital communications (159,160).

Although SARS remained a relatively small outbreak, it received extensive media coverage in countries not affected by it, including the Netherlands (161), Norway (162) and the United States (60). The reports emphasized the ability of global travel networks to spread new diseases quickly, rendering the simplest interactions "potentially fatal on a global scale" (163).

2.4.5 Public responses to the outbreak and to media coverage

The rapid circulation and variety of information about SARS complicated the already-difficult task of preventing the spread of SARS itself. As one historian noted,

"In an era in which information could circle the world within seconds, the SARS virus initially outraced vital knowledge about treatment and control" (138). In both Hong Kong Special Administrative Region and Toronto, it was difficult for public health experts to stay ahead of what the public knew, which in turn made it difficult to present a consistent, workable containment plan to the larger public (141,142). In Hong Kong Special Administrative Region, anger over how local authorities handled the outbreak contributed to one of the largest peaceful protests in its history (164). In Toronto, the outbreak did not produce public protests; however, despite public health assurances that the virus was not race-specific, ethnic Chinese residents and their businesses did experience discrimination (165).

2.4.6 Overall findings and conclusions

The SARS outbreak, which first inspired the use of the term infodemic, illustrates a range of information-related problems (166). Scientific experts faced political pressures to downplay the outbreak's extent and severity, which may have delayed information sharing and, thus, measures that might have slowed the spread of SARS. A reluctance to share information with affected communities created information voids that spurred alternative forms of communication as well as substantial distrust in authorities. Overall, the challenge of information management during the SARS outbreak was compounded but not created by greater access to the internet. One observer noted that SARS saw a growing number of people "becoming part of a global information community who track down and exchange information online" (167). However, traditional media also played an important role in amplifying both information and mis- and disinformation.

3. DISCUSSION

3.1 Strengths and limitations of the scoping review

A strength of this scoping review is the way it combines broad perspectives and in-depth studies of historical cases. The structured search of literature on information-related problems during past epidemics generated questions and hypotheses that could then be explored in the three historical cases. The choice of the 1918 influenza pandemic, the early AIDS pandemic in the 1980s and the 2003 SARS outbreak was effective first because these represent particularly significant episodes in the formation of modern public health practice, and secondly because all have been the subject of extensive, high-quality historical studies. The historical literature chosen for close analysis was based on extensive primary and secondary research, ensuring that solid generalizations and comparisons could be made.

Still, the report might be criticized for using the concept of an infodemic as the focal point for investigation. This concept is difficult to define and understand, as applied to both current and past events (7). Drawing overall conclusions about information-related problems from a review of different historical outbreaks also inevitably involves simplifying complex phenomena. As is true of any historical phenomena, the three cases analysed in this review featured important differences that limit the generalizations that can be based on them. The timing and mode of spread varied for each pathogen: the 1918 influenza pandemic and the 2003 SARS outbreak followed the pattern of a classic epidemic, spreading widely and guickly fading away over the space of months, whereas HIV/AIDS had a far more complex pattern of spread occurring over years, not weeks, and the global pandemic is far from over even now. The nature of the pathogens also affected the degree of stigma and resistance to public health measures that they inspired: as fast-moving upper respiratory infections, the 1918 influenza and 2003 SARS outbreaks produced less push-back compared with HIV/AIDS, an infection associated with sexual activity, intravenous drug use and extreme poverty. The 1918 influenza outbreak also occurred during a multicontinent war, which introduced military and security issues into its handling that did not exist for the other outbreaks. Another limitation of the chosen historical cases relates to the fact that none involved vaccination campaigns because no vaccines were available (108). Therefore, they offer little insight into the current problems of vaccine avoidance and resistance, although they do highlight factors that fuel distrust of experts and public health advice.

A final limitation of the report is the fact that the findings are based primarily on English-language literature, with the majority of authors based in western European countries, the United States, Canada and other Commonwealth nations. The perspectives of colonial and post-colonial nations are underrepresented, which limits the scope of the conclusions. The decision to include only peer-reviewed works with formal citations and bibliographies may also have excluded insights from non-traditional actors. All these choices limit the generalizability of the findings outside western European and North American countries.

3.2 Potential relevance of the historical findings to contemporary infodemic management

The findings of this scoping review suggest that infodemics are not new, but that their intensity has increased over the past 50 years for reasons discussed below. However, it is important not to overstate their significance, as the term has become widely used without an extensive evidence base, and research on the impact of mis- and disinformation associated with disease outbreaks is underdeveloped (7,168).

This review confirms a key point raised in the literature: abundance of information alone does not create information-related problems. In fact, such problems have multiple causative factors: political context/timing, the characteristics of the disease, the degree of scientific understanding, historical legacies, official sanction, the activities of the media, and pre-existing patterns of public understanding of and trust in public health recommendations. Underreporting and/or active suppression of information can also create problematic information voids (43,61).

This review also confirms that information-related problems reflect wider issues, such as the distortion, amplification or rejection of information to advance political agendas or for other social, economic or cultural reasons. The historical cases highlight some of the mitigating factors emphasized in the structured literature search, such as high levels of public confidence in health experts and government leaders (38); acknowledgement of the limitations of scientific knowledge as it is evolving (23,24); acknowledgement of the role of politics, values and priorities in public health policy (35,44); and the active participation of affected groups in developing and exchanging information (23,24).

Overall, the historical analysis suggests that infodemic management during disease outbreaks requires not just new forms of social media surveillance and

management but also broader strategies designed to account for inevitable uncertainties around the production and consumption of information about a new pathogen. These uncertainties need to be addressed both online and offline across three linked domains: the scientific and expert community, the mass media and the public.

The following sections present more detailed findings relative to the specific research questions chosen for the scoping review.

3.2.1 Roles of scientific uncertainty and disagreement on containment and mitigation strategies

In infodemic management, the main focus is on the later stages of the amplification process, that is, the negative downstream impacts of traditional and social media's circulation of mis- and disinformation. Historical analyses suggest the value of paying more attention to the earlier, upstream genesis of infodemics: the ways that dynamics within the scientific community (including the need for debate to reach consensus and the competition to be first to report a finding) inadvertently contribute to mis- and disinformation.

Scientific uncertainty about a new pathogen and its threat level is unavoidable but is a core contributor to an infodemic. In all three historical cases, identifying the pathogen and anticipating its threat level required integrating very different types of scientific evidence – laboratory tests, epidemiological trends and direct observation of the spread of disease. This process required a kind of applied science known as disciplined guesswork (169). With more and better data, the results of that guesswork improved, but early statements also proved wrong and had to be corrected. This process of revision became the source of potential misinformation – for example, that the 1918 influenza was just *la grippe* (66) or that AIDS was a gay-related immune deficiency (94) – and contradicted expectations that the tools of modern science could swiftly and accurately diagnose infectious disease threats.

In each of the examined outbreaks, policy experts had to translate imperfect, complex scientific findings about the pathogen and its behaviour into guidance about specific containment and mitigation measures. These measures were weighed against economic, political and human-rights concerns. Tensions between public health efforts to slow infection and concerns about the epidemic's economic impact were evident in the 1918 pandemic: businesses sought to limit measures that might result in economic losses. The HIV/AIDS pandemic generated high levels of

stigma and public alarm that fuelled support for strategies against the spread of the virus, such as travel bans and criminalization, despite their ineffectiveness. The business community viewed the SARS outbreak as the "kiss of death" in a world where international trade and investment were perceived as the "main engines of prosperity" (138). Multiple studies have shown that the impact of SARS on economies was smaller than media reports and model estimates suggested at the time, yet the perception that public health measures might have dire economic consequences remained a prominent concern, especially from the travel and tourism industries (143,148).

Ongoing global economic interdependence has increased the sense of vulnerability to new viral threats, including the use of bioterrorism by nation states and individual groups; as a result, pandemic preparedness has become an economic and national security issue in addition to a public health issue (137,170,171). In the era of COVID-19, the economic fallout of repeat lockdowns has generated concerns about widespread social and political destabilization. These trends have made it all the more difficult for experts to attempt to operate outside politics, and to resist political and economic pressures from government and business leaders (38).

To improve expert messaging, it is vital to acknowledge the uncertainties of knowledge production and the competing concerns involved in deciding upon its application. When confronted with a novel pathogen, it takes time for laboratory research and epidemiological modelling to produce the data needed to revise and improve containment measures. These measures also reflect a process of decision-making that inevitably prioritizes some concerns over others. This reality should not be glossed over in public health communication, but instead should be acknowledged and explained so that the public better understands and tolerates these dynamics. Efforts to build public health literacy while reducing anxiety and confusion could include more discussion of how scientific enquiry proceeds and why its findings require continual revision.

A final observation that emerged from this scoping review is the need for research scientists and public health experts to use caution in their own references to past pandemics. Historical references may have unanticipated consequences, as they did when scientists publicly pointed to the genetic similarity between the 1918 influenza virus and the early-21st century H5N1 virus (53,54). Overall, the three historical cases have been and continue to be prolific sources of lessons learned – lessons invoked in scientific publications and covered in the mass media.

3.2.2 Role of existing information technologies and their ability to share expert guidance with the public

The extent and variety of media outlets expanded over the 20th century, creating opportunities to amplify information, including mis- and disinformation. Historical perspective underlines the ways that old forms of media have evolved to coexist with new forms, creating an increasingly complex information landscape. By 1918, new electronic technologies (telegraph and telephone) had shortened the time needed to transmit information over long distances from weeks to minutes, while innovations in print technology made cheap newspapers available in many cities and towns. This information highway carried news of the influenza pandemic as it moved from locale to locale, as well as public health messages about protection measures the public needed to take. During the 1918 pandemic, patterns of information sharing reflected the era's top-down notions of public health authority.

By the time of the AIDS pandemic, radio and television had been added to the mix. As print and electronic media competed with each other to attract audiences, the volume, variety and velocity of information they offered increased. Between the AIDS pandemic and the SARS outbreak, technological revolutions produced a very complex information landscape that offered far more diverse outlets for reporting on and responding to a pandemic. The expansion of the internet spurred hopes that digital media might make the dissemination of information more equitable. In the 1990s some activists saw the internet as a platform for the exercise of more democratic, grassroots power. Without the access barriers created by elite actors (including the mass media), users could expand their own universe of knowledge (172). At the same time, this openness created the conditions for further destabilizing of what constituted reliable information. During the 2003 SARS outbreak, personal electronic devices that allowed access to the internet complicated rather than simplified information management.

Since the early 2000s, technological changes have facilitated the shift from passive to interactive use of digital resources. New forms of computer software have made it easier for people to interact, create and share online content with one another. This more interactive digital world, often referred to as Web 2.0, has made it possible for people to generate and disseminate their own unfiltered understandings of pandemic events and policies. From a long-term historical perspective, this more interactive digital information landscape is undeniably a significant development. However, the findings of this review suggest that infodemic management should not focus too heavily on social media but should also consider the influence of traditional

media – and the way that the old and new interact. In promoting media efforts to slow misinformation, the focus should not be just on digital platforms (Facebook, Instagram, Reddit, TikTok, Twitter, YouTube and similar outlets) but also on the role of newspapers and radio and television broadcasts. Indeed, older media may have more credibility in some contexts and among certain communities. The beneficial aspects of greater media diversification and wider public participation in media dissemination should also be considered, as the current focus is predominantly on the negative.

3.2.3 The public's ability and willingness to understand, accept and act on expert guidance

The findings of this review suggest that novel disease agents produce a cycle of scientific uncertainty and confusion that, while understandable and predictable, contradicts the expectations of both policy-makers and the public of what science should and can do. In fact, a wide range of players – scientists, governments, mass media outlets and corporations – have contributed to unrealistic expectations about how fast science can act when faced with a novel threat. Failure to deliver on such promises, coinciding with growing public and media criticism of science and policy-makers, provides fertile ground upon which infodemics can flourish.

In 1918 the prestige of science was high and the sense that ordinary people had the skills to critique it was low. Responses to the influenza pandemic were shaped by existing narratives about the need to support the war, support the returning soldiers and bring the terrible conflict to an end. Although scepticism about germ theory and the origins of influenza existed among alternative health groups, it had limited coverage in the mainstream newspapers. By the time of the AIDS pandemic, a more critical stance towards scientific expertise had developed and the diverse media landscape disseminated often-useful challenges to official claims and policies. Citizen and community groups sought to fill information voids themselves, rather than rely on experts to do so for them. The response to the SARS outbreak showed similar characteristics.

Comparison of information-related problems over time confirms an observation made in the social scientific literature: that audiences learn to navigate the media dissensus produced by diverse media platforms (7). Through successive information revolutions, many people became accustomed to the volume, velocity and variety of information available to them and developed ways to manage it, such as seeking out preferred sources of information and practising selective attention to tune in or out what interested them.

Historical comparison also points to the influence of broader changes in disease experiences in shaping what audiences pay attention to and anticipate having to do. In high-income countries, strong public health infrastructure and faith in medications have created a false sense of security, and knowledge about the importance and efficacy of physical distancing measures declined as a result (173). Media characterization of public health tools such as quarantine as harsh and health experts' focus on the power of modern medicine to deliver effective technical solutions such as vaccines further undermined public support for a wider array of effective strategies. Since the Second World War, addressing health risks has been increasingly cast in terms of individual choice rather than as protecting the public. These long-term trends are important to consider when developing contemporary public health messaging.

In more specific ways, the findings presented here suggest the role of historical legacies in shaping public responses to disease threats. Experts are not the only ones who might refer to past experiences of disease: individuals and communities may also have memories of and associations with past outbreaks that shape their response to current challenges. Distrust of authority often reflects previous negative experiences with the moralization or criminalization of disease issues in past outbreaks. To appreciate why some forms of misinformation about past health issues seem so persistent, it is important to consider not only cognitive and psychological factors (174,175) but also historical ones.

For these reasons, historical perspectives may be useful in expanding the scope and effectiveness of prebunking scripts, which aim to debunk false or misleading information before it begins circulating. Historical analyses help to identify persistent forms of misinformation that resurface during subsequent disease outbreaks. This perspective has been very useful in understanding vaccine hesitancy and refusal, and might be extended to other public health topics as well (176). Historical findings can also be used to call attention to the potential for political and commercial interests to use disease outbreaks for their own ends. Research on prebunking strategies suggests that alerting citizens to the existence of disinformation and the groups actively spreading it helps them to become more critical consumers of information (175); adding historical examples could support that objective.

Finally, this historical review confirms the principle long recognized within public health that the messenger matters as much as the message. Quality information is more likely to be taken up if shared by sources who already have public support. Analyses of successes and failures in past practice reinforce the commitment in

contemporary infodemic management to "listening to community concerns and questions, promoting understanding of risk and health expert advice, building resilience to misinformation, and engaging and empowering communities to take positive action" (1). Trusted sources of information include local contacts who understand and listen to their community's concerns. To really engage with people's beliefs, concerns and misunderstandings, two-way communication is crucial, and can be especially effective when developed with the active participation of affected communities.

3.3 Areas for further historical research

As discussed in section 3.1, perhaps the most important area for future research is the development of information-related dynamics and issues outside of western European and North American countries. The impact of post-colonialism, new information technologies and persistent inequalities in the resources available to the Global South compared with the Global North need deep and careful study.

Another topic that warrants more historical work is the tension inherent in balancing the need to share information with concerns about producing counterproductive fear or panic (69,73). As the three historical cases showed, during past disease outbreaks, health-care professionals, public health officials and government leaders have hesitated to share what they know out of concern that disclosing the seriousness of a disease risk might spur counterproductive behaviours such as fleeing, hiding and avoiding screening tests. The same concerns have sometimes shaped media coverage of disease outbreaks. More in-depth, interdisciplinary study of how panic has been invoked in public health decision-making and messaging is needed, particularly as, historically, this risk seems to have been overestimated.

Perspectives from the social sciences, including cultural anthropology, social psychology, sociology and history, might also provide insight into effective ways to mobilize the instinct for human preservation, at both the individual and community levels, and address how social and cultural factors can undermine the appeal of public health advice or make adherence to such guidelines impractical or impossible. Further recognition of and research on the major role of civil society groups in shaping and delivering public health messages and programmes could also strengthen important networks of collaboration.

A final area for additional research is the impact of deliberately easing expectations of careful peer review during public health crises. Since the beginning of the

HIV/AIDS pandemic, the scientific community has realized the need to quickly share findings during a disease outbreak and, to that end, has relaxed processes of peer review to facilitate faster data sharing and interpretation. While necessary, this fast-tracking may become a potential source of mis- and disinformation. More study of how much of a problem this has become in recent decades might help the bodies responsible for ensuring high-quality scientific findings (scientific associations, journal editorial boards and public health agencies) find ways to mitigate its effects.

3.4 Policy considerations

The findings of the review yielded several policy considerations for mitigating the risks and impacts of infodemics. These build on experience in infodemic management and align with the core tenets of WHO guidance on risk communication and community engagement while emphasizing new developments for further strengthening responses to infodemics. The main policy considerations are to:

- ensure that policy measures aimed at mitigating infodemic risks anticipate and address broad societal concerns related to the role of experts, trust in authorities and other issues that are difficult to address through technocratic solutions;
- engage with diverse media sources (including television, print and social media) to disseminate information to wide audiences, and ensure that information is not being withheld or censored;
- nurture grassroots and local interactions to disseminate accurate information about disease outbreaks and public health measures by collaborating with civil society and ensuring that affected groups actively participate in information development and exchange;
- implement measures to improve public health literacy and increase awareness of the factors that inform how scientific knowledge is translated into public health guidance during a public health emergency;
- adopt prebunking techniques, informed by historical analyses of the forms of misinformation that have been prevalent and recurrent across past disease outbreaks, in order to counter areas of historically grounded mistrust and misunderstanding;

- acknowledge scientific knowledge gaps, the potential for information to change and the limitations of fast-tracking the dissemination of research findings in order to limit public concerns relating to inconsistency in expert messaging and avoid undermining the credibility of and trust in scientific information as new evidence emerges in ongoing disease outbreaks;
- consider the historical legacies as well as the social and cultural factors that shape public attitudes towards and levels of trust in information channels when determining who is best placed to disseminate health messages in specific contexts (for example, public health authorities, government officials, civil society representatives or other actors); and
- promote or restore public confidence in government leaders, public health experts and organizations before emergencies occur.

4. CONCLUSION

Infodemics flourish in the expectation gap between an idealized faith in science and the hard realities of what science can produce at short notice. Over the last 50 years, this expectation gap has widened due to changes in how science is done, how science is presented and perceived, how scientific communication occurs both among experts and with the public, how that communication is amplified by new information technologies and competitive media outlets, and how people are expected to understand and act on expert guidance. As a result, infodemics have become more complex and more intense in their impacts.

In responding to a global disease outbreak, information is not a panacea. Management strategies based on the belief that improving the quality and speed of digital information sharing will counter an infodemic will not succeed. New pathogens invariably outrace the capacity of even the fastest surveillance and monitoring systems to detect misinformation about them. Moreover, the relationship between accurate or inaccurate information and its impact on adherence to public health advice is complex. Developing health literacy, critical thinking and an understanding of how misinformation is created and used will be crucial for managing future infodemics.

It is likely that another novel disease will emerge within the next half-century on a par with the 1918 influenza pandemic, HIV/AIDS, SARS or COVID-19, but management strategies based on past outbreaks may be ineffective against new disease threats that spread in very different ways. This highlights the importance of teaching generic prebunking and debunking skills. These include learning to evaluate the reliability of sources through fact-checking, but also anticipating that some individuals and groups will actively seek to spread false information.

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ANNEX 1. SEARCH STRATEGY

A hermeneutic approach

As a discipline that straddles the social sciences and the humanities, history uses a critical research method very similar to that of hermeneutic review, an interpretive process that is described in detail in Annex 2 of Health Evidence Network synthesis report 49 on the use of narrative methods in the health sector (1). Historians study texts using "two interlinked hermeneutic cycles: accessing and interpreting the literature and developing the argument" (1). In addition, historians are trained to analyse both primary sources (documents from the time) and secondary sources (interpretations of these documents by historians). In using these sources, an awareness of historical context – for example, what a term meant at the time it was used – is essential. Historians strive to avoid overly simplistic ahistoricism (assuming that what is true today was true a hundred years ago) and instead ask, What are the continuities, legacies and shifts between the past and the present?

Initial broad search

A hermeneutic approach involves exploring the genealogy of important concepts through the use of keywords, defined as "a shared body of words and meanings" that underpin general discussions "of the practices and institutions which we group as culture and society" (2). Therefore, the search strategy for this scoping review began with a broad search for the keywords "infodemic" and "infodem"" between May 2021 and August 2021 to determine their prevailing uses and the challenges they represent. This search was not limited by date or language, and encompassed scientific, grey and popular literature. Academic literature was searched in PubMed. The searched grey literature included WHO reports and guidance supplied by experts in the field of risk communication, management and assessment. The citation pearl method, a systematic process of refining search terms, investigating references of references and tracking citations forward (1), was used to identify additional sources that provided deeper perspective on these concepts. Findings were discussed with WHO staff members directly engaged in infodemic management to identify especially important issues. Finally, popular literature was searched in Nexis Uni, a database of newspapers, business and legal stories, wire services, broadcast transcripts, international news, and non-English-language sources.

These records addressed the following issues related to infodemic management during a global pandemic:

- the problem of scientific uncertainty during a public health crisis;
- the need to revise guidance when new data comes in as an inadvertent source of misinformation;
- the impact of pre-existing patterns of mistrust and suspicion that complicate risk communication about a novel pathogen; and
- the complexities of a changing media landscape.

Discussions of these issues in the infodemic literature commonly used the following concepts and terms to concretize the difficulties of information sharing during a pandemic:

- the qualities of the information itself (volume, velocity, variety, value and veracity);
- the distinctions among information, misinformation and disinformation;
- the filters and institutional factors that regulate these qualities and distinctions;
- the role of the information-misinformation-disinformation triad in disrupting effective risk communication and management during an outbreak;
- the differing capacities of specific media forms, that is, traditional, print, electronic, broadcast, cable, and new media that rely on computers and the internet, to contribute to an infodemic; and
- the underlying attitudes towards scientific expertise and government authority that influence how information is understood and acted upon.

Systematic, structured search

Insights gained from the broad search informed the development of the second step of the search strategy, which involved reframing the contemporary understanding of an infodemic as an historical problem. A systematic, structured search was conducted to answer the question: How have the factors identified as affecting an infodemic (qualities of information; distinctions among information, misinformation and disinformation; filters; methods of risk communication; media capacity; and conditions of trust) changed over time? Combination keyword searches were conducted in two databases designed for systematic searching, limiting the results to citations up to the end of 2019.

In Web of Science (Arts and Humanities), the search terms used were ("outbreak" OR pandemic OR epidemic) AND ("risk communication" OR media OR news OR radio OR television OR "misinformation" OR "disinformation" OR "infodemic") in TI Title OR Topic OR AB Abstract or Author-Supplied Abstract OR KW Author-Supplied Keywords and excluding book reviews.

In EBSCO Historical Abstracts, the search terms used were ("outbreak" OR pandemic OR epidemic) AND ("risk communication" OR media OR news OR radio OR television OR "misinformation" OR "disinformation" OR "infodemic") in TI Title OR SU Subject Terms OR AB Abstract or Author-Supplied Abstract OR KW Author-Supplied Keywords, excluding unpublished theses.

Records were included if they focused on:

- factors that may have historically contributed to an infodemic; and/or
- factors that may have mitigated the risks of an infodemic during an infectious disease outbreak/epidemic/pandemic.

Records were excluded if they were not research based (for example, if the citation led to a historical source) and/or if they focused on:

- a communicable disease but pre-20th century;
- a noncommunicable disease;
- hypothetical or mythical outbreaks;
- outbreaks confined to animals;
- the role of media/information spread/misinformation/rumours, etc. broadly, but without a link to any specific infectious disease outbreak;
- risk communication best practice, but without a link to a specific infectious disease outbreak; and/or
- media related to the coverage of a specific infectious disease outbreak but without a direct focus on factors that may contribute to an infodemic.

The structured search yielded 284 records, of which 48 were deemed relevant after title/abstract review and 44 were directly cited in the review.

Focused search on three historical cases

Following the structured search, three historical cases were chosen for closer examination (the influenza pandemic of 1918, the beginning of the HIV-AIDS pandemic in the 1980s and the SARS outbreak of 2003) based on the following criteria:

- they had a global impact, affecting multiple countries in the same time frame;
- the pathogens involved were relatively new and produced high rates of illness and death;
- they had extensive short- and long-term impacts on public health practice;
- they occurred after the development of mass media (forms of communication capable of reaching many people as a public health crisis unfolds); and
- to mitigate the impact of the pathogen in the absence of vaccines, public health authorities attempted to contain the spread through mass communication and the imposition of non-pharmaceutical measures (quarantine, health education and risk communication, and social distancing measures).

The examination of each historical case began with a search of EBSCO Historical Abstracts, World Cat (for books and edited collections), and JSTOR and Project Muse (for articles). To make the comparison manageable, the historical studies focused primarily on European countries, Canada and the United States, but included synthetic works that surveyed other regions of the world to develop a comparative perspective. For each study, a set of search terms relative to that specific disease event was identified: for the first, the terms "influenza", "pandemic", "World War 1", and "Spanish flu" were used; for the second, the terms "HIV" and "AIDS" were used, and the search was limited to records that focused primarily on the 1980s; and for the third, the term "SARS" was used.

Full-text assessments were carried out. Records were included if they focused on at least one of the following issues in the context of each historical case:

- the problem of scientific uncertainty during a public health crisis;
- the need to revise guidance in the light of new data as an inadvertent source of misinformation;

- the impact of pre-existing patterns of mistrust and suspicion that complicate risk communication about a novel pathogen; and/or
- the complexities of a changing media landscape.

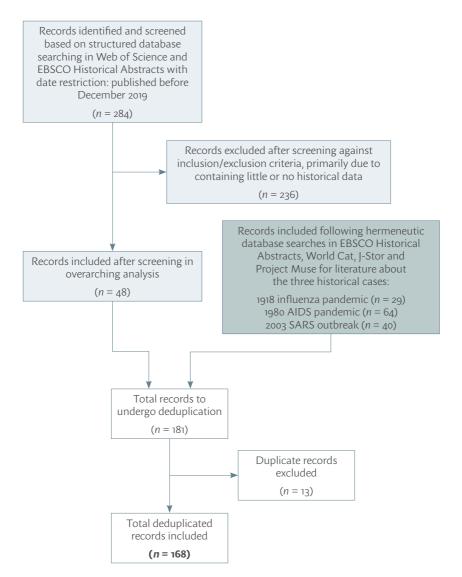
Records were excluded if they:

- lacked formal references or footnotes;
- did not directly address the factors identified above; and/or
- were not based on research in primary documents or only mentioned the relevant disease, outbreak or health topic in passing.

A total of 132 records (including 12 already identified in the structured search and one article relevant to both HIV/AIDS and SARS) met the inclusion criteria: 29 on the 1918 influenza pandemic (all of which are directly cited in the review); 64 on the early HIV/AIDS pandemic (of which 55 are directly cited in the review); and 40 on the 2003 SARS outbreak (of which 33 are directly cited in the review).

After deduplication across the three phases of the search strategy, this scoping review included a total of 168 records (Fig. A1.1).

Fig. A1.1. Selection of studies



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ANNEX 2. ADDITIONAL BACKGROUND MATERIALS³

A total of 20 articles were identified in the searches but are not directly cited in the main text: four were from the structured search (1–4), nine from the searches to inform the historical study on HIV/AIDS (5–13) and seven from the searches to inform the historical study on SARS (14–20).

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