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Public responses to infectious diseases outbreaks: the role of emotions

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Thesis submitted in accordance with the requirements for the degree of

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of the
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LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

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Declarations

I Antonis Kousoulis, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without the prior written consent of the author.

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About the Student

I am the Director for England and Wales at the Mental Health Foundation – a national UK-wide public mental health charity of over 70 years. In my role at the Foundation, I steer and oversee our Research, Interventions and Policy work, and lead a department of 50 people.

I qualified in Medicine at the University of Athens, Greece, and have completed an MSc on Medical Humanities shared between Imperial College London and University College London.

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I have published over 100 papers in peer-reviewed journals which have over 950 citations. I have peer reviewed extensively (incl. receipt of two “Honors for Outstanding Reviewer” by the American College of Physicians), and have done over 160 presentations at regional, national and international events. My teaching activities include visiting appointments at Oxford University Nuffield Department of Primary Care, the London School of Hygiene & Tropical Medicine Global Mental Health Centre, and the University of Crete Public Health postgraduate centre.

I have a particular interest in risk and inequality in the context of public health (understanding, mapping, responding, communicating), as well as power, social determinants, real world evidence, and historical methods. I also have a strong interest in managing organisations, and kind and inclusive leadership.

ABSTRACT

BACKGROUND: Infectious disease outbreaks account for significant global costs in human lives, social implications, and financial burden. It is considered possible to minimise the consequences of catastrophic viral outbreaks through advance preparation and effective communication. To prepare effectively, it is important to understand the political, social, economic and cultural factors that impact on the epidemic spread and shape human responses and action. Despite the capacity of human emotions to influence all these issues, they have been largely neglected in public health.

AIM: To ascertain if there are emotional determinants impacting population responses to infectious diseases outbreaks and understand how such emotions are influenced by the social and wider determinants related to the local context where outbreaks emerge.

METHODS: A systematic review that explores the differences in public responses by emotion, infection, outcome and region, and five in-depth case studies of infectious diseases outbreaks at a national level to understand how responses are shaped by the local and global context of the time.

FINDINGS: There are emotional determinants that influence public responses to epidemics and pandemics and impact on the uptake of interventions. To improve the effectiveness of public health communications in the face of emerging outbreaks, certain important messages emerged in my research, including the need to disrupt the power dynamics of “top-down” communications, build trust between global and local actors (as well as with governments), and harness the potential role of traditional media and social media for good and connection. Which emotions are evoked through public health communications is also important, as fear and panic were shown to be counterproductive in promoting uptake of interventions, but worry and empathy emerged as key motivators for action.

CONCLUSIONS: Both in the context of the COVID-19 pandemic and for future emerging infectious diseases outbreaks, emotions need to be considered in crisis communications.

Abstract word count: 300

LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune-deficiency syndrome
ALP	Australian Labour Party
ART	Antiretroviral drugs
ASHM	Australasian Society of HIV Medicine
AUD	Australian Dollar
AZT	Azidothymidine
CDC	Centers for Disease Control and Prevention
CEO	Chief executive officer
Cont.	Continent
CoV	Coronavirus
COVID-19	Coronavirus disease 2019
DrPH	Doctor of Public Health
ECHI	European core health indicator
EID	Emerging infectious disease
EMB	Education and Manpower Bureau
Etc.	Etcetera
EU	European Union
EUR	Euro
EVD	Ebola virus disease
FDA	Food and Drug Administration
GDP	Gross domestic product
GISN	Global Influenza Surveillance Network
GOARN	Global Outbreak Alert and Response Network
GRID	Gay-related immune deficiency
H1N1	Hemagglutinin Type 1 and Neuraminidase Type 1
H5N1	Hemagglutinin Type 5 and Neuraminidase Type 1
H7N9	Hemagglutinin Type 7 and Neuraminidase Type 9
HAART	Highly active antiretroviral therapy

HBM	Health belief model
HCDCP	Hellenic Centre for Diseases Control and Prevention
HIV	Human immuno-deficiency virus
HKD	Hong Kong dollar
HPV	Human papilloma virus
IDU	Injection drug user
IHR	International Health Regulations
IV	Intravenous
IVU	Intravenous user
LGBT+	Lesbian, gay, bisexual, trans and other sexuality identities
LSHTM	London School of Hygiene & Tropical Medicine
MERS	Middle East respiratory syndrome
MeSH	Medical subject headings
MetaQAT	Meta Quality Appraisal Tool
MMT	Methadone maintenance treatment
MSM	Men who have sex with men
N/A	Not available
NACAIDS	National Advisory Council on AIDS
NCHVR	National Centre in HIV Epidemiology and Clinical Research
NCID	National Center for Infectious Diseases
NEP	Needle and syringe exchange programme
NSW	New South Wales
OHCHR	Office of the High Commissioner of Human Rights
PCR	Polymerase chain reaction
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
Pub. Year	Publication year
SARS	Severe acute respiratory syndrome
SIV	Simian immunodeficiency virus

SPEECH	Society and politics, economy, epidemiology, culture, healthcare and public health
STD	Sexually transmitted disease
SUS	Sistema Único de Saúde
US	United States
USD	United States dollar
y.o.	Years old
WCW	Woohwangchungsimwon
WHO	World Health Organization
ZVD	Zika virus disease

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SUMMARY OF KEY MESSAGES AND RECOMMENDATIONS

The key recommendations and messages emerging from the evidence in my thesis are:

- Key messages and recommendations:
 - There are emotional determinants that influence public responses to epidemics and pandemics and impact on the uptake of interventions.
 - Fear- and panic-based public health campaigns do not work.
 - The power dynamics of “top-down” communications need to be disrupted.
 - Post-colonialism and other abusive histories should be acknowledged and new trust-building initiatives designed between global and local actors.
 - The role of media at times of epidemics needs to be reconsidered.
 - To meaningfully appeal to emotions, public trust building is necessary well before an outbreak.
 - There is a place for more listening and empathy in public health communications.
- In public health practice:
 - Consider emotions in crisis communications and work with trusted leaders.
 - Communicate risk clearly, honestly and transparently.
 - Co-produce public health communications and measures.
- In public health research:
 - Define emotions clearly in studies, and study emotions in conjunction with beliefs.
 - Study emotions using new frameworks and conceptualisations, including as ways of coping, through psychobehavioural surveillance or with the appraisal tendency framework.
 - Use ethnographic research methods.

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INTRODUCTION

“A crisis is the sum of intuition and blind spots, a blend of facts noted and facts ignored.”

(Dr. Michael Crichton)

Quoted in “The Andromeda Strain”, by Michael Crichton; Arrow: London, 1993.

1. INTRODUCTION

Crises and risk

Based on several interpretations of history, it has been argued that *crisis* is what qualifies history into being history. In the words of Professor of Anthropology Janet Roitman: “*crisis is the means to access history; it marks and generates history*” [1]. However, historians have wondered whether it would actually be possible to narrate a non-crisis history and have debated how helpful or unhelpful it is that the political discourse consistently tends to differentiate between periods of crisis and periods of *normalcy* [1]. It would certainly be a challenge to a historian to identify any universal periods of normalcy in our highly interconnected world and, hence, the very definition of normalcy might suffer from a lack of examples. Similarly, historical sociology is often understood as a discipline that was born of societal crises with an aim of proposing diagnoses of crises and contribute to their end [2].

It is generally much easier to define and provide examples of crises, even if one sticks to the definition from the 1970s when a science of crisis started to take shape [2]: “*crisis is a collective stress situation, where many members of a social system fail to receive expected conditions of life from the system*” [3]. Unpredictable elections, divisive referenda, the politics of populism and nationalism, war and population displacement, climate change debates, financial markets crashes, and pandemics are just a few examples that have been experienced as crises, at least by certain sections of the population in certain countries. And this is just in the two decades of the current century.

Interestingly, however, over the decades, the expectations of communities and populations from the “system” have evolved and now vary widely. It seems that, increasingly, most crises would be classified as of the dissensus type. Dissensus types of crises are defined as conflict-containing situations where there are sharply contrasting views of the nature and the situations, what brought it about, and what should be done to resolve them [4]. Thereof, many crises are, to a certain extent, crises of confidence, or linked to crises of confidence (such as towards the system, to government interventions, between investors and lenders). It is important then, to examine arguments and evidence about a crisis’ relationship to economic, social, demographic, political and environmental change and explore the development and implementation of multifaceted responses to them. It is also important to remember that by “responses” we mean

reactions of human beings, and human reactions are often governed by emotion and are influenced and amplified through interaction.

These human reactions are influenced by factors that exist long before a crisis emerges and are largely shaped at the early stages of a crisis, when the *risk* of a crisis becomes apparent. From the threat of predators in pre-historical times, to the natural and non-natural hazards lingering above societies and cultures today, risk is an undesirable, yet unavoidable subject for all humans. Risk often triggers thoughts and reflections, and at the same time instigates strong emotional responses. Looking at newspaper articles reporting disasters and social media feeds sparking controversy, we not only process these messages cognitively, but also experience them emotionally [5]. Our judgments and choices concerning a crisis in our external environment are not only governed by cognitive thinking, but also by emotional responses, as are they in the cases of internal crises (for example, an infection) and the external impacts that this has [6]. Risk, then, as a central theme that delineates the perceptions of human beings as they interact with the external world, warrants scholarly attention from both the cognitive and affective domains [7].

Epidemics and pandemics as global crises

When studying crises, it is not unreasonable to use infectious disease outbreaks as good examples of crises that test the capacity of societies to manage disaster. These are crises that can also divide communities along the lines of blame and inequality [8]. In fact, the term “crisis” has its origins in the Greek language with a meaning at the cross section between law, medicine and theology, but it is the medical meaning that was dominantly used and without interruptions until the 17th century when the term started expanding into politics, economics, history and psychology [9]. To generate useful public health insights from the study of infectious diseases outbreaks as crises, we would almost need to de-medicalise epidemics and approach them as both “*crises in context*” and “*crises as context*” [8].

Infectious disease outbreaks are often experienced on the ground as catastrophic events or disasters testing the local society. Of course, such disasters do not just happen. Anthropologists have argued that for a disaster to take place there needs to be a conjuncture of two factors (a human population and a potentially destructive agent) and a conducive context. Similarly, epidemiologists have developed a model of triad for infectious disease causation (an external agent, a susceptible host, and an environment that brings them together) [10]. It is that context,

the environment, of a historically produced pattern of vulnerability that will make the disaster unavoidable. This place-based vulnerability is evidenced in the location, infrastructure, socio-political organisation, production and distribution of systems and resources, and ideology of society [11]. When hazards threaten and disasters occur, they both reveal and become an

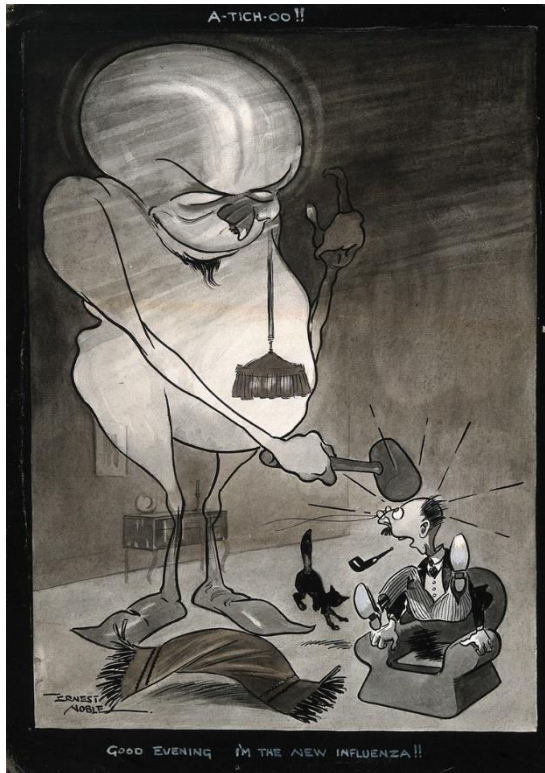


Figure 1.1. A monster representing an influenza virus hitting a man over the head as he sits in his armchair.

Pen and ink drawing by E. Noble, c. 1918.

Credit: Wellcome Collection.

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expression of the complex interactions of physical, biological, and socio-cultural systems. A society's pattern of vulnerability is, in fact, a core element of disaster as it conditions the behaviour of individuals and organisations far more profoundly than the physical force of the destructive agent [11]. In other words, how people and systems respond to both the risk of and the actual epidemic is, in most cases, a stronger predictor of how destructive it will be than the potential of morbidity and mortality that the causal virus has.

Perhaps the best understood example is influenza (Figure 1.1). Flu disease is an acute viral infection, the most common infectious condition affecting human populations [12]. The aetiological cause of influenza, the Orthomyxoviridae family of viruses, was first

discovered in 1931 and was isolated from humans in the United Kingdom in 1933 [13]. The three types of flu virus (A, B, C) can infect humans, with type A also being able to cause disease in birds, pigs and other animals [14]. Influenza can occur as seasonal outbreaks (three to five million cases every year) [15], or in the form of a pandemic. The influenza virus remains a well-established and concerning public enemy, despite new research that improves our understanding of it. For example, studies using animal models and human population research have both detected significant pre-symptomatic influenza transmission, suggesting that successful containment is very unlikely for human-adapted influenza viruses that transmit efficiently within populations [16, 17]. It is also linked to the rising concerns of bioterrorism, with the World Health Organization (WHO) suggesting that it is not considered feasible to significantly halt the spread of a pandemic virus [18]. Similar concerns have been raised in recent years for a

number of emerging and re-emerging infectious diseases, including Ebola virus disease, Zika virus disease and COVID-19.

From the history of epidemics and pandemics, it is apparent that outbreaks occur somewhere in the world in most years. Annual, regional and seasonal epidemics are due to antigenic drift (small mutations of viruses that can lead to changes in the surface proteins of the virus and make it capable of triggering an immune response); and pandemics, occurring at 10 to 50 year intervals, are due to new virus subtypes resulting from virus re-assortment and subsequent antigenic shift (major changes in a virus that can then infect humans) [19, 10]. On average, three pandemics per century have been documented since the 16th century, most often attributed to influenza viruses [18]. A pandemic is an epidemic occurring worldwide or over an extensive area, crossing international boundaries, and usually affecting a large number of people [20]. The WHO has designed a global influenza preparedness plan. Its latest update redefines the six phases of pandemic alertness, in which Phase 6 – Pandemic Period – refers to *“increased and sustained transmission of a new influenza virus subtype in the general population.”* The rationale for this phase is that major changes in global surveillance and response strategy are required since pandemic risk is imminent for all countries [18].

However, even though we have learned an enormous amount about the epidemiology of pandemic viruses in these past centuries, and especially the 20th century, our approaches to the control of the disease seem rather primitive and reactive. Even though we widely accept that pandemics are an outcome of long-term, complex and interrelated processes, their outbreak is most often experienced on the ground as an unexpected eruption [21]. We wait until there is a new strain and a significant population has suffered from it before developing a control strategy for the rest of the world. As a rule, it is done under stress, as was the case in 1918, 1957, 1968, 1977, 2009, and more recently with COVID-19 [22].

This context has now finally triggered a significant body of research on preparedness, surveillance, and prevention in recent years [23]. We have more clearly defined the vulnerabilities invoked by intense globalisation and created actor-networks that are primed for rapid mobilisation to manage “known-unknowns” [24]. Shared and interactive co-determinants of disease emergence have been extensively documented and studied. It is increasingly evident that infectious disease outbreaks are not a new phenomenon related to modern life, but there are more basic determinants, transcending time, place, and human progress, that govern disease emergence (a clear overview of these is provided in the next chapter). By examining

historical epidemics we can uncover cases similar in many of their features [25], and this should help further improve our preparedness and prevention plans. Even well before the COVID-19 pandemic, the health argument for preparedness and prevention was clear. There were clear concerns that, because of increased globalisation, infectious diseases appearing in one country can spread rapidly to others, and cause catastrophic impacts on the global economy [26]. Modelling suggested that a pandemic caused by a respiratory virus such as the one in the 1918 influenza pandemic, would today spread to most urban centres globally and kill 33 million people in the first six months [27]. The economic argument is equally grave as a severe global pandemic could cost the global economy as much as USD 3.5 trillion and hit the global gross domestic product (GDP) by 5-10% in one year [28]. These predictions have been put to the test by COVID-19, and though less deadly than the 1918 pandemic so far, it has led – through the lockdown measures – to the biggest economic slowdown on record with about a third of the global population in lockdown [29], millions of businesses having to close for indefinite periods and a projected reduction of 6.7% of working hours globally [30].

Given the current ongoing threat posed by the COVID-19 pandemic and the constant presence of emerging infections and outbreaks across generations, it is essential to become more able in our response to epidemics and pandemics as significant crises.

Emotional responses to crises and risk

Responding effectively to epidemics has a lot to do with how the public respond to the risk posed by an outbreak as a crisis and what behaviour they follow based on public health recommendations. Health behaviours of the public are important at the early stages of high-risk epidemics and can be a critical factor in how an outbreak spreads. People respond to risk differently, and risk communication can be difficult. Lack of trust to the agencies imposing interventions can lead to health programmes failing with harmful consequences, but building and maintaining trust is challenging in an environment and time when the public is wary and distrustful of institutions [31].

In public health, a key example of these shifting attitudes and increasing distrust is vaccine hesitancy – taking immunisations as the key public health measure to control infectious diseases led by institutions. Vaccine hesitancy refers to delays in the acceptance or refusal of vaccination despite the availability of vaccination services [32]. The factors associated with vaccine hesitancy vary across time, place and vaccines. It is not new as an issue (having originated at the time of antonis.kousoulis@lshtm.ac.uk 2020 21

the first introduction of compulsory vaccination in the mid-1800s), but, again, it is linked to global phenomena, having grown as a movement through the use of online platforms [33]. For example, when considering accepting the vaccination of their children, some parents experience conflicting thoughts of risk underestimation (in relation to the severity of a disease) and risk over-perception (in relation to the safety of the vaccine). This is a highly emotional thought process [34], and these opinions are not being driven by facts (the truth), but by emotion (often manipulated emotion), and by what appears to be true [35].

Public health authorities' responses have been to go back and explain the evidence. However, this persistence in conveying the truth and this faith in the ability of others to understand it is increasingly seen as a potentially fatal error [35]. There is a lot more to influencing behaviour change than evidence. Most people's perspectives are based on life experience, their values, opinions of others they are close to, and often even those that do look for evidence tend to ignore it if it does not confirm their existing world views. Objective facts are interpreted in subjective ways [36].

The way that people understand risks and make decisions under crises conditions relies, not only on statistics and science, but also on intuition and heuristics – simple, efficient principles which serve as mental shortcuts and reduce the complex tasks of assessing probabilities and predicting values to simpler judgmental operations [37]. Behavioural research shows that different individuals may have different probabilities for the same event and a key heuristic impacting on that is the *"affect heuristic"*, that is the use of emotions and gut responses to judge benefits or risks [37, 38]. Based on the notion of the affect heuristic, people make decisions and judgements by consulting their emotions, through substituting a difficult question (*"What do I think about this?"*) with a much easier question (*"How do I feel about this?"*) [39]. The process of the affect heuristic suggests that, if a general affective view guides perceptions of risk and benefit, then perception regarding risk can be changed (or affected) by receiving information about the benefit – and vice versa. Indeed, studies on decision-making in conditions of uncertainty have shown that intuitions and feeling are often the biggest driver of decisions, and they are in turn affected by each person's environment and context [37].

However, this is not to suggest that intuitions and feelings are irrational, disorderly or individualistic. Psychological research on crowd responses to disasters has shown that emergencies often create a sense of common fate and social support [40]. Official guidances assuming a panicking or passive public incapable of taking the responsibility needed when crisis

strikes fail to acknowledge people’s capacity for self-control and collective behaviour in the face of an external threat [41]. Similarly, prosocial behaviour is a key factor in health outcomes as well, and it can be influenced by what information is given to people and how and from whom this information is delivered.

This evidence ought to shift the conversation also in the context of epidemics and risk perceptions to the key individuals and groups (usually: the public as recipients of interventions, and the government and state as agents of the interventions). Since behavioural and psychological research suggests that people are predisposed towards, or away, from a stimulus through a reliance on emotions and crowd psychology, then, similarly, emotions would influence how people respond to public health recommendations based on their evolving relationship with the state and experts. It may be then that emotional responses are much more than that (responses), and have the capacity to be the missing link in what determines the course of an epidemic. Especially since infectious diseases outbreaks and other public health emergencies are more than health events and occur in highly charged political, social and economic environments [42].

From emotional responses to emotional determinants: study rationale

The understanding of and experience of working with emotions has been steadily evolving over the decades and centuries. “Emotion” as a term originated from French in the early 17th century, initially as a word denoting physical disturbance and bodily movement. In the course of the 18th century, it increasingly came to be connected to mental feelings, but not necessarily with a clearly agreed scientific definition, before beginning to be more standardly used in early 19th century [43]. The slow journey of the evolution of the terminology and lexicon of emotion, however, does not necessarily suggest that these emotional notions were entirely new or necessarily distinct from historical uses of terms such as “passions”, “melancholy” and “affections of the soul”. Critically though, this linguistic transition of “emotions” into the scientific and psychological discourse of the 19th century – and to this day – followed the work of the early theorists of emotions who made an attempt to de-medicalise the concept and disconnect emotions from their pathological associations [44].

Taking the anthropological approach, then, to emotions is interesting as research and scientific study in this space has focused heavily on whether emotions are biologically based or culturally constructed. The historiographical evidence on this seems to be very consistent with the modern

understanding of emotions. In bridging the biological and constructionist sides of the argument, it is convincing to suggest that emotions do not constitute fundamental genera. Rather, they are shaped by, and are shaping, practices and social norms linked to each person's experience. The latter is, of course, further dependent on historical, social, cultural, spiritual, and other factors [45].

In this context, contemporary psychological research has focused on appraisal theories to explain how different emotions in different people may emerge from the same event, by using information from the circumstances, people's concerns, expectations, and history [46]. Appraisal theory defines emotions as processes, rather than states. It links emotions to action through a number of components: (i) an appraisal component with evaluation of the environment and people's interaction with it, (ii) a somatic component influencing people's physiological responses, (iii) a subjective experience of feelings component, and critically in the case of my study (iv) a motor component with expressive and instrumental behaviour and (v) a motivational component with action tendencies and readiness [47]. Appraisal theories assume that there is a variable relation between stimuli and emotions, but a stable relation between appraisals and emotions. Following on this long tradition of appraisal theories suggesting that discrete emotions mediate the relationship between cognitive appraisals of stimuli and individuals' behavioural responses [47], the Appraisal Tendency Framework has been proposed as a useful theoretical lens linking one's discrete emotions with their cognitive appraisals. There are two important dimensions to this framework that explain these connections. First (appraisal), specific emotions are the product of specific cognitive processes; second (tendency), emotions induced by previous stimuli or experience can sustain their influence on later judgments, choices, and actions [48].

Despite a wealth of psychological research in this space and its application to emergencies and disaster responses, there has not been a systematic gathering of knowledge on emotions in the context of public health and epidemics. Hence, my study, above all, attempts to analyse and comment on the particular roles of emotional determinants which impact on decision-making and behaviours in the context of these longer-lasting public health crises.

Of course, outside of the field of public health this is not a new topic. In fact, it has been studied substantially in behavioural economics. Sectors such as advertising and fundraising have been drawing from insights on emotions for decades. Marketing attempts to draw customers through triggering memorable experiences suffused with emotion [49]. Fundraising sees people

fundamentally as emotional decision-makers, requiring an emotional connection to change their behaviour or get motivated to act (in this case, to donate) [50]. However, the Institute of Fundraising's Fundraising Regulator's Code of Practice has warned against producing fundraising materials that intend to trigger distress [51]. Research in this sector has shown that when people feel extreme unpleasant emotions (such as guilt and fear), they can go into a state of withdrawal, and would be unlikely to take action and donate [52]. Instead, evoking compassion, empathy, pride and belonging, is much more likely to produce a positive outcome [53].

To explain these relationships, behavioural economists have looked to the science behind rewards and the affect heuristic. Fundraising and advertising that put too much emphasis on "need" do not achieve the desired outcomes, at least certainly not in a sustainable long-term manner. Reward feelings are more important for consistent action and behaviour change [54]. Similarly it can be said for public health campaigns that when they are patronising, instructing people what to do, with little taking account of local, social and cultural context, they would fail to trigger the feelings of reward for those that take up the recommended actions. These relationships have not been clearly explored in public health yet. Most research has focused on emotions such as panic, fear and anger, while the role of emotions in public health decision-making and of pleasant emotions, in particular, has been largely neglected.

My thesis focuses on emotional determinants impacting on the response to epidemics (which may be relevant to other health crises as well). As such, the focus is on a point in time, a snapshot. For example, I am not assessing attitudes towards AIDS and how these change over time; I am assessing how attitudes and emotions towards AIDS impacted health behaviours when AIDS emerged and was considered a crisis. In this research, I conduct a systematic review and primary historical research, and examine arguments and evidence on the presence of emotional determinants in public responses to epidemics. I explore their relationship with economic, social, political, and cultural factors and change processes that lead to the development and implementation of multifaceted responses to epidemics as crises. I explore case studies in settings with recent memories of crises. Whilst I produce targeted localised histories, I differentiate this project by commenting on the intersections with global influences and critically reflect on the historical forces that have shaped global health and driven local consequences. In doing this, I generate lessons from the past and support long-termism and maintaining a historical perspective on things. Those can help inform how we respond to epidemics – including the ongoing response to the COVID-19 pandemic which is having a

significant emotional impact [55] – how public health professionals can refine our risk communications, and how we study epidemics from a multidisciplinary perspective.

Study aims

In this context, my research aims are:

- To ascertain if there are emotional determinants impacting population responses (with a focus on health behaviours) to the risk (or perception of risk) of infectious diseases outbreaks and what evidence supports those determinants.
- To understand how such emotional determinants are influenced by the social and wider determinants related to the local context where outbreaks emerge.

METHODS

“Our comforting conviction that the world makes sense rests on a secure foundation: our almost unlimited ability to ignore our ignorance.”

(Daniel Kahneman)

Quoted in “Thinking, Fast and Slow”, by Daniel Kahneman; Penguin Books: London, 2011.

2. METHODS

Overview

The key research methods for my thesis include:

1. Literature review: An original systematic review (on literature from the past 30 years) on emotional determinants and their impact on public responses to infectious diseases outbreaks and their risk.
2. National case studies, from the past 30 years, of outbreaks and the role of emotions in the response to them at a level of specific nations.

This combination of secondary literature research and primary historical research is intended to provide new evidence on how emotional determinants impact on public behaviours. The study of the literature aimed to uncover, synthesise and critically appraise the evidence base on this neglected topic. The case studies add a nuanced understanding of if, and how, these determinants work in the real world, based on their interaction with other social and contextual factors influencing and shaping emotions and responses at a local level. In the Discussion section, I draw the key themes from across all the evidence sources to produce relevant recommendations. This is an interdisciplinary project and, as such, I draw evidence from (among others) health, historical, psychological, behavioural, environmental, sociological, anthropological, organisational management and sustainability research.

Operational definitions

For the purposes of this thesis, certain operational definitions were followed to ensure a shared language and understanding of the topic.

It is not the purpose of this review to participate in the legitimate debate around the classification of emotions. It is increasingly recognised that emotions emerge as a combination of physical properties in human bodies, brain reactions to the environment, and one's own culture and upbringing [56]. The theory of constructed emotion was used to underpin the study of emotional determinants in this work, according to which: *“our brain uses past experience, organised as concepts, to guide our actions and give our sensations meaning. When the concepts involved are emotion concepts, our brain constructs instances of emotion”* [56]. In other words,

emotions do not occur in a vacuum, rather they are constructed based on human responses to external stimuli and they have the capacity to influence or guide peoples' actions.

In this context, the *emotional determinants* of health have received increased interest recently [57], based on evidence that decisions about health are not only reliant on cognitive processes but also impacted by hopes, fears, anxieties and feelings that interact with political and social determinants [57, 37]. Emotional determinants of public responses to the risk of epidemics in this review have been classified as specific human emotions that may influence an outcome (in this case the uptake of public health interventions).

Epidemic refers to an increase, often sudden, in the number of cases of a disease above what is normally expected in that population in that area. *Outbreak* carries the same definition of epidemic, but is often used for a more limited geographic area. *Pandemic* refers to an epidemic that has spread over several countries or continents, usually affecting a large number of people [10]. To better define epidemics and pandemics, some additional criteria such as how many countries were involved, and the excess of morbidity and mortality, are often also needed, even if these are collected mainly retrospectively [58].

To allow a more comprehensive study of distant or recent epidemics, several other “qualitative” features, beyond morbidity, mortality and spread, such as decisions, actions, reactions, and the social context, are needed. In this work I venture towards an in-depth understanding of human responses to epidemics in the context of risk. The emotional impressions that historical events leave on populations are equally – or perhaps more – important than a quantitative analysis. A history only based on data and focusing on scale may fail to conceive and personalise disaster in human terms and forget faces and reactions so that events become just numbers [59, 60]. In the words of Albert Camus in *“The Plague”*: *“Since a dead man has no substance unless one has actually seen him dead, a hundred million corpses broadcast through history are no more than a puff of smoke in the imagination”* [60].

Hence, in order to be able to comment on the emotional determinants and response to epidemics and extract learnings for the future, I am prioritising the outbreaks that, through a range of social resources (such as social capital or belonging), have been placed into our collective consciousness [61]. In this context, I am approaching our collective memory of epidemics as originating in shared communications that generate the meaning and form of the narrative on each crisis, as well as the symbols and signs that surround it [62].

Literature review

A review following the principles of the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) [63] was conducted to assess the available research on the presence and value of emotional determinants and how they impact public behaviours at times of epidemics, in relation to the uptake of public health interventions. The Methods for the review are outlined in detail in chapter 3 (Literature Review).

Case studies (historical research)

The national case studies were conducted using historical research methods. For each case study, available primary sources were explored and used, including newspapers, popular magazines, some satirical cartoons, and contemporary scientific journals articles to capture the evidence of the era. In addition, online search tools that indexed and documented available primary sources were explored. Selected scholarly historical books and peer-reviewed journal articles have been used as secondary sources.

There is an inherent challenge when studying responses to epidemics at the time when they emerged. This is particularly true when the infectious disease and nature of spread were not entirely scientifically understood. Hence, complementing primary research with secondary sources or studies published retrospectively, helps bring perspective to the historical view.

In this thesis, I aim to show that emotions are relevant and important factors when it comes to considering individual or population responses to an emerging epidemic. However, emotions are not produced in a vacuum. Recent research shows that humans construct emotions using a conceptual system which transforms inputs from the world, independent from their personal being, into feelings that are relevant to their context [56]. Hence, emotions are a social reality influenced by a number of contextual factors, that is the social, economic and cultural circumstances in which we exist. My historical research on emotions, then, as is the case with any historical research, needs to be carefully contextualised into the reality of the era studied. Therefore, in an attempt to define and classify emotional determinants, it would be an oversight to not acknowledge existing public health evidence on social and other determinants. In fact, chances are that there is a high interrelation between a variety of factors, especially when it comes to how we respond to infectious diseases.

Developing a framework to contextualise and systematise my historical research

Rationale

Disease incidence has historically served as an index and comment on society [64]. Current public health thinking on the determinants of health focuses on the life course through examining the material and social conditions in which people are born, grow, work, live and age, and on the structural drivers of these conditions, the distribution of power, money, and resources [65]. It is known that vulnerable groups are disproportionately affected by infectious diseases [66], and the level and distribution of wealth within a society play a significant role in determining vulnerabilities to communicable diseases [67]. Such social inequalities have persistently influenced both the distribution of emerging diseases and the course of disease in those affected by them [68]. However, despite a robust evidence base, these determinants are still often neglected when governments and healthcare systems are designing interventions. Their interplay with population emotions is even more neglected.

Significant strides have been made in the past decade in terms of what types of evidence are being considered when addressing epidemics, since 2001 when Professor Chris Potter wrote that *“it seems that nothing of note has been introduced during the past 100 years to affect the recurrent pattern of epidemics and pandemics”* [19]. The influence of a broader mix of factors – including and beyond the social and economic ones – are now recognised as determinants of infectious disease morbidity and mortality [69]. Transitional patterns following historical and socio-cultural events can provide instrumental cues to modifiable behaviours [70]. Effectively addressing outbreaks means no longer debating whether to focus on social or medical, biological or environmental factors but to take multidisciplinary approaches considering all these factors in conjunction with each other [69]. However, most of the research on the determinants of infectious disease spread, especially following the recent and much studied example of the flu pandemic in 2009, has largely focused on the determinants of disease severity and outcomes [71, 72], or on vaccine acceptance [73, 74] and communication strategies [75].

Hence, a broader interdisciplinary framework that includes social and other contextual factors [76] is needed to allow a more comprehensive in-depth study of epidemics in my thesis and enable commentary of how emotions play a role in public responses. I set out to create a framework here, to be used for the study of historical outbreaks at a national level.

Rapid review methodology to develop a framework

To achieve that, a rapid literature review was performed based on a systematic approach framework proposed by the WHO and used to inform health policy and systems [77]. Rapid reviews are a method to synthesise knowledge in which systematic review processes are accelerated, and methods are streamlined to complete the review more quickly than is the case for regular systematic reviews [78]. This methodology was chosen, not only due to the limitation of conducting a systematic review with only a single reviewer, but also because rapid reviews, when following a systematic framework, are intended to provide actionable and relevant evidence in a timely and cost-effective manner [79]. Hence, this review was conducted as a priority-setting exercise to inform the relevant emerging research and policy agenda that this work is trying to define on emotional determinants [77, 80].

The rapid review was conducted by a single reviewer, without verification by a second reviewer, but responsibility for a study screening, selection and data extraction was reasonably led by an experienced reviewer with a track record of conducting relevant reviews [81, 82, 83, 84, 85]. The review followed to the extent possible the PRISMA guidelines and standards [63].

Publications of interest were identified through a search of PubMed/Medline, the Cochrane Library and Google Scholar, the latter especially for additional grey literature. A staged searching approach was used first to identify existing systematic reviews, then studies and publications with other designs that provided the most rigorous secondary or relevant primary evidence. As most often is the case in rapid reviews [77], the search was streamlined by being limited by date (a nominal limit of the past 30 years – since 1988 – was used, for consistency with my main systematic review), language (publications only in English) and study design (secondary research, or primary research with a clear focus on non-clinical determinants), with no contact with authors. Search terms were selected from both Medical Subject Headings (MeSH) and other glossary databases. The identified terms included: epidemics, pandemics, social determinants of health, socioeconomic factors, economic recession, one health, politics, and public health. Data extraction was limited by the scope of the review, and a bespoke data abstraction framework was used as a template for recording significant study characteristics, with a focus on relevant neglected determinants.

The extracted key determinants were recorded using a simple bespoke form, and subsequently, the determinants were classified under broad categories under the wider societal and community factors of a standard socio-ecological framework [86]. In the first instance, the

common European Core Health Community Indicators (ECHIs) [87, 88] were used to inform the thinking of this classification. ECHIs include four main categories of indicators understood as one category for the relevant outcome (health status) and three for its determinants (demographic and socioeconomic factors, health systems including health promotion, and determinants of health). However, further classification was undertaken to combine the determinants under categories that would more logically and precisely work in the case of the study of outbreaks. An iterative approach leading to a narrative summary was employed for the results, as is common in rapid reviews [77], and no further statistical or other analyses were undertaken. As the studied research was predominantly secondary and no fatally flawed studies, as suggested in the framework by Dixon-Woods et al. [89], were expected, no further quality appraisal was conducted.

For the synthesis of the evidence, in order to keep my historical research relevant to public health policy, practice and research, I chose the type of rapid which provides a “map” of the key themes and topics addressed by previously published primary and secondary research [90].

Lead Author	Year	Publication type	ECHI categories addressed
Farmer [68]	1996	Secondary, Perspective	Health systems, Determinants of health
Stephens et al. [91]	1998	Expert panel	Demographic and socio-economic factors, Health systems
Smolinski et al. [92]	2003	Book	Health systems, Determinants of health
Morens et al. [12]	2004	Secondary, Review	Demographic and socio-economic factors, Determinants of health
Phua et al. [93]	2005	Secondary, Overview	Health status, Demographic and socio-economic factors
World Health Organization [18]	2005	Report	Health systems, Determinants of health
Morens et al. [25]	2008	Secondary, Review	Demographic and socio-economic factors, Determinants of health
Brien et al. [94]	2012	Secondary, Review	Health status, Demographic and socio-economic factors

Lowcock et al. [71]	2012	Secondary, Routine data	Health status, Demographic and socio-economic factors
Kousoulis et al. [95]	2014	Secondary, Routine data	Health status, Determinants of health
Quinn et al. [96]	2014	Secondary, Review	Health status, Demographic and socio-economic factors, Health systems
Grantz et al. [97]	2016	Secondary, Routine data	Demographic and socio-economic factors, Determinants of health
Quick et al. [98]	2018	Book	Health systems, Determinants of health

Findings of the rapid review

A total of 41 studies were identified through the database search, nine of which fulfilled the criteria of comprehensive secondary research. A further four publications were identified through a hand search of the references of the included studies, and searches in the grey literature. A brief overview of the included studies is provided in Table 2.1 classified under the ECHIs framework. A total of 26 determinants were extracted from 13 publications (Table 2.2). These factors include microbiological, socioeconomic, political, meteorological and genetic determinants.

Table 2.2. Population factors involved in epidemic emergence and spread	
Animal disease ecology	Media and social media influences
Breakdown of public health measures	Microbial adaptation and change
Changing ecosystems	Poverty and social inequality
Climate	Preparedness (planning, governance, surveillance)
Confidence between systems actors	Presence of genes from human strains
Economic development and land use	Public trust in governmental interventions
Economic recession and austerity	Season
Education	Severity of illness
Geographical location	Technology and industry development (including agricultural intensification)
Government and political system	Vaccination availability and trust
Human behaviour	

Human demographics and crowding	Virus’ rate of transmission
Human resource and infrastructure	War and famine
Intent to harm	
International trade and commerce	

A framework to study past epidemics (SPEECH)

Out of the 26 identified factors, I have prioritised the 16 that are most relevant to the intention of this study to almost “de-medicalise” epidemics and take a public health view by considering a broader ecosystem of influences. Hence, the main focus here is not solely on the epidemiology, but also on the political, social, economic and cultural factors that impact on the perceptions of risk and shape emotional responses to infectious disease outbreaks. In Table 2.3, I have summarised and categorised these 16 relevant determinants, using the acronym SPEECH (Society and Politics, Economy, Epidemiology, Culture, Healthcare and public health) for ease of reference and memory of the multi-faceted framework.

- Society and Politics: Social structures and social and political determinants are critical in influencing how a nation or region responds to an epidemic threat. In most past and recent examples of infectious diseases outbreaks cases and deaths have been distributed according to a social gradient [99]. Emerging infectious diseases are influenced by a circle of viral-social-political-ecological interactions, and narratives and response heavily depend on the state of government, institutions, and the confidence and levels of trust between their stakeholders [100, 31].
- Economy: The link between economic downturns and emerging infectious diseases is well evidenced. Not only are periods of recession sometimes followed by epidemics (as poorer living circumstances facilitate the spread of infections), but also health outcomes are worse during recessions [101], and larger epidemics often have severe economic impacts [102]. Further, poverty and financial inequality are key drivers of morbidity, mortality and distribution of an infectious disease [25].
- Epidemiology: The epidemiological characteristics of an infection, such as how serious an illness it causes or whether it is transmitted through direct or non-direct contact, can impact how people respond to its risk. Understanding epidemiological dynamics, however, can be challenging during an outbreak when mortality rates may be high and practical concerns, such as the safety of healthcare workers, need to be prioritised [103].

Coupled with demographic, environmental and geographical factors that affect transmission and spread [25, 104], responses can vary heavily depending on the nature of the infection.

Table 2.3. The SPEECH framework of key factors interacting with emotions in relation to epidemic emergence and spread.

<i>Area of Study</i>	<i>Relevant Determinants</i>
SOCIETY & POLITICS	<i>Government and political system</i> <i>Human demographics and crowding</i> <i>Public trust in governmental interventions</i> <i>War and famine</i>
ECONOMY	<i>Economic recession and austerity</i> <i>Poverty and social inequality</i>
EPIDEMIOLOGY	<i>Geographical location</i> <i>Severity of illness</i> <i>Virus' rate of transmission</i>
CULTURE	<i>Confidence between systems' actors</i> <i>Human behaviour</i> <i>Media and social media influences</i>
HEALTHCARE & PUBLIC HEALTH	<i>Breakdown of public health measures</i> <i>Vaccination availability and trust</i> <i>Human resource and infrastructure</i> <i>Preparedness (planning, governance, surveillance)</i>

- Culture: The cultural context in a country is often a critical mediating factor in how both public health professionals, governments and the public respond to an epidemic, or the risk of it. This is linked to broader questions of how people are influenced by others and by the specific contexts in which they live [105]. Media have an important role here, as their coverage is often what provides the framing for an emerging infection [106], which is further amplified in modern societies by the capacity of social media platforms to spread dis- or mis-information based on a variety of media sources blended with personal views and commercial interests [107].
- Healthcare and public health: Issues such as the state and funding of national or regional healthcare systems, governance, surveillance systems, and the resilience of public

health systems often steer the direction that an epidemic will take in a specific area, hence impacting on citizens' responses [23]. Vaccines remain, of course, one of the most effective way to intervene at a population level during an epidemic, but a decline in public confidence has been noted in the past couple of decades, which is also driven by a range of psychological, sociocultural and political factors [108].

Accepting that these complex and interrelated social, economic, political and demographic factors – rather, processes – contribute in tandem to the emergence and spread of outbreaks and the public's responses to them, would call for using the framework of syndemics. In syndemic theory, it is proposed that factors such as the above – for example violence, poverty, infrastructure – and the spread of infectious diseases are not separate phenomena occurring concurrently, but are closely related [109]. Recognising the interaction between and fluidity of these issues, my historical research will use the factors outlined in this framework to study the outbreaks at a national level in depth. A consistent structure for each will be used based on this framework.

Addressing historiographical issues in using the SPEECH framework

Despite the relevance and interactions between the 16 identified determinants, more often than not, when outbreaks occur, they are experienced on the ground as short-term catastrophic events (as opposed to long-term processes leading to their emergence), with a need to attribute to a single cause [21]. Hence, it is important in this research to combine a scientific understanding of these persistent and long-term determinants with the public understanding of how such events transform social resources and affect local communities for much longer than the duration of the international and government emergency responses.

This premise is not entirely new. In 1996, a perspective in the journal *Emerging Infectious Diseases* posed the question of “*how large-scale social forces influence unequally positioned individuals in increasingly interconnected populations*”. It further called for a critical epistemology of infectious outbreaks and an analysis of social factors and inequalities that contribute to the epidemic emergence and spread, arguing that such an analysis should be historically deep and geographically broad, incorporating concepts of change [68].

Then, around ten years later, another perspective in the *Journal of Public Health Policy* identified serious gaps. It proposed that the traditional public health research approach should be combined with broader sociological analysis in order to develop a better and deeper

understanding of what factors affect the occurrence of epidemic disease outbreaks, and, eventually, lead to developing better programmes to combat disease outbreaks [93].

Yet, another decade later, in 2014, the *Cambridge Anthropology* journal devoted a whole special issue to the gaps in relation to the analytical question that has remained neglected in medical anthropology and medical humanities as a whole: “*What is the relation between the epidemiological reality of outbreaks as conditioned by long-term social, political economic, demographic and ecological factors, and the empirical reality of outbreaks as ruptures of the social, political and economic continuum*” [21, 110]?

Emotions clearly interact with a large number of determinants to produce responses. Common and interactive co-determinants of outbreak emergence and spread have been increasingly documented and studied. There are fundamental determinants, typically acting in concert, that seem to underlie the emergence and spread of as well as response to epidemics. In this Doctorate of Public Health (DrPH) research, I aim to bring together the research understanding on these persistent and long-term determinants with the public emotional understanding of how such events transform human, financial and social resources, and therefore influence our responses to them. In this process, and so that I will be able to comment on the impact of emotional determinants, I will delve deeper into factors such as public perceptions and reactions, the concurrence of economic and other social crises, cultural responses, and how epidemics trigger the collective emotional consciousness.

A note on the use of the language of “determinants”

I am not in my thesis trying to argue that emotions are a sole motivator of health behaviours or an isolated cause of failure of public health interventions. Instead, I am attempting to uncover where emotional determinants have been the missing link in responding to epidemics. In some cases, my reader might consider that it is not emotions that are the key determinant of behaviour, rather disinformation, lack of international coordination or limited resources. I should note, then, that notwithstanding its multidisciplinary nature, my thesis remains a public health study. In public health, determinants are understood as factors that influence health outcomes. These factors are influenced by the circumstances in which people are born, grow, live, work and age, which are further shaped by people’s social and physical contexts, and communities’ historical experiences. These, in turn, are affected by the distribution of money, power and resources at global, national and local levels (Figure 2.1). Taking this “causes of the

causes” approach [111, 112] suggests that it is meaningful to focus down on emotional determinants, whilst taking into account those broader influencing contexts and factors.

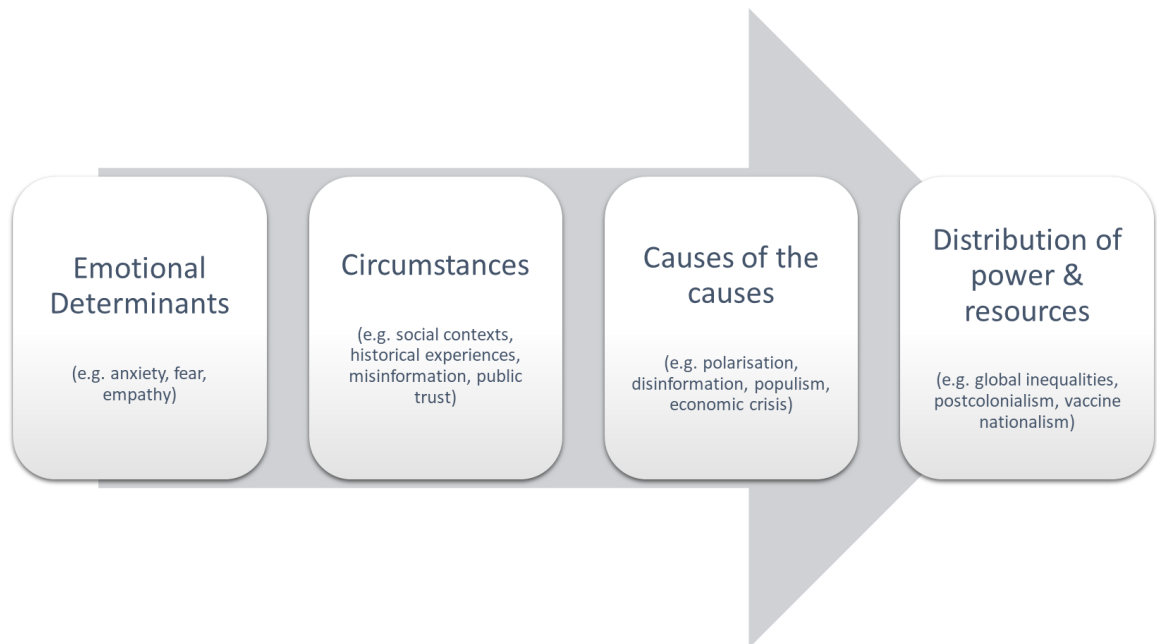


Figure 2.1. The "causes of the causes" approach applied to emotional determinants.

LITERATURE REVIEW

“The problem is not that the term “emotion” has no clear meaning, but that it has many meanings.”

(Dr Carroll E. Izard)

Quoted in Izard CE. More meanings and more questions for the term “emotion.” Emotion Review. 2010;2:383–385.

3. LITERATURE REVIEW

Aims

A literature review was conducted to identify relevant research to assess the presence and value of emotional determinants, as well as consider how they impact public responses to the risk of infectious diseases outbreaks, specifically in relation to uptake of public health interventions.

Research questions included:

- (i) Are emotional responses (to the risk, or perception of risk, of infectious diseases outbreaks) of the public influencing their uptake of public health interventions?
- (ii) How do these emotional determinants differ when considering specific emotions and which emotions act as motivators for action?
- (iii) To what extent do these determinants vary by continent and region and type of infection, and what is their impact in cases of high risk groups?

Methods

A literature review was conducted by one researcher, following the principles of PRISMA [113].

Operational definition of emotional determinants

As above, emotional determinants of public responses to the risk of epidemics in this review have been classified as specific human emotions that may influence an outcome, in this case the uptake of public health interventions [56]. In my thesis, a basic consensus approach was followed in which emotional stimuli are categorised as being either pleasant or unpleasant, and predispose people to bivalent behaviour (such as approach or withdrawal) toward the stimuli [114]. All emotions generally motivate some sort of action as a response to the eliciting event, but, broadly speaking, unpleasant emotions behave like red-alert buttons focusing attention on a problem, whilst pleasant generally arise in safer situations [115]. A range of emotions was studied in my thesis and it is important that these are clearly defined and categorised to enable some quantitative analyses. It is not the purpose of this study to comment on the role of emotions in human thriving or suffering, or the socially-constructed morality of those [115], rather I have adopted the long supported biosocial framework that all emotions are essential in evolution and adaptation [116]. Hence, from this point of view all emotions that humans experience are useful, they are not irrational, and their triggering is rationally explained based on individuals' contexts [117].

Emotional determinants were extracted from included manuscripts and assessed on their own right. For sensitivity and more in-depth analyses, they were also assessed in groupings of pleasant emotions, unpleasant emotions, high-intensity unpleasant (extreme) emotions and anxiety-related (moderate) emotions [118]. This framing is also consistent with a very recent report on pandemic emotions and COVID-19 [119]. It was considered that this is not contradictory to the latest evidence on emotions, and as covariates like region and population were also factored in, it is largely consistent with the modern contextual interpretation of emotions. In recording emotions in this review in this way, I have started from one of the traditional classifications between “pleasant” (including emotions such as hope, love, happiness, joy, and empathy) and “unpleasant” emotions (including sadness, fear, anger, and worry) [120] (also see Table 3.4). These are motivated from a, culturally interpreted, distinction between an appetitive system associated with positive or pleasant feelings and an aversive system associated with negative or unpleasant feelings [121], but these terms are, in no way, used here to suggest an association with rationality, or with happiness and wellbeing. Positive psychology research suggests that emotions can be positive in some contexts and negative in others, regardless of whether they are pleasant or unpleasant [122].

To classify emotional determinants into these groupings, to support my quantitative sensitivity analyses, I undertook an informal consensus approach (whilst acknowledging the limitations in how these terms are recorded in the literature). Following the systematic search of the literature and initial data extraction, terms from relevant studies referring to emotions were recorded. To establish some inter-rater reliability, I asked a small group of expert colleagues at the Mental Health Foundation to classify those terms into the four suggested groupings above and then compared and contrasted their proposals. To establish face and content validity for emotions as determinants, I asked an expert epidemiologist colleague at the Vaccine Confidence Project to read 12 of my included papers at random and feedback on the correlations between emotions and outcomes that I had recorded.

For the terms for which there was no initial agreement, a method of discussing with colleagues until reaching consensus was followed and some concessions in the definitions of emotions had to be made for quantitative purposes: apathy, indifference and lack of threat awareness were all grouped together as “apathy”; wishful thinking was combined with “hope”; intense fear of a conspiracy and negative consequence was combined with “panic”. These only affected a total of four correlations and were not expected to significantly impact on the results. It should also be noted that the emotions of anxiety, worry, stress and concern, though broadly describing

similar reactions, were initially recorded and analysed separately following how they were mentioned in the various included studies, but they were then also grouped together for sub-analyses as “anxiety-related or moderate emotions”. Lastly, “surprise” was not included among the emotional determinants in this review as it was taken, through consensus, as a state linking cognition and emotion with the capacity to intensify emotions [123], hence, could not be correlated directly to outcomes.

Many of the terms referring to emotions are often used interchangeably in the literature with little critical thinking or have multiple definitions (ranging from clinical to folk uses) attached to them. Hence, it is important to be clear on how the emotions recorded in the review are understood, especially in the context of them being interpreted as possible determinants of behaviour. I adopted the following definitions for the emotions identified in my literature searches:

- Anxiety: the affective (emotional) equivalent of uncertainty [124], especially in response to perceived vulnerability or susceptibility [125].
- Apathy: a lack of feeling, passion, or interest; lack of participation or action, loss of motivation, indifference to threat awareness [126].
- Concern: feeling of anxiety in relation to a perceived uncertain threat [127].
- Empathy: used in this study in its popular psychology sense meaning openness to the emotional perspective of another [128]; includes: perspective taking of another person, staying out of judgement, recognising emotion in other people and communicating this, feeling with other people [129].
- Fear: an immediate, concrete and overwhelming feeling of physical danger. As such, fear is distinct to anxiety (mainly in the perception of threat being concrete, rather than uncertain) [130, 131], and fear-related behaviours can be defined as individual or collective behaviours and actions initiated in response to reactions that are triggered by a perceived threat or actual exposure to a potentially traumatising event [132].
- Hope: goal-directed thinking, characterised by the potential and motivation to find routes that lead to desired goals and thoughts [133]. In health settings hope is understood hope as arising from the confidence that everything humanly possible will be done for the good of the person at risk (or patient) [134].
- Hopelessness: understood as the lack of hope, with negative emotional and motivational impacts [134].

- Panic: panic is perhaps the most challenging term to find an agreed definition on and a tension continues to pervade definitions of panic [131]. Historically, it has long been associated with infectious disease. It can be construed as a normal social phenomenon to explain extraordinary departures from routine [135], though it has acquired a collective folk usage over the years as a form of primitive “hysteria”, predominantly associated with the public (or subordinates or “natives” in other historical contexts), rather than the authorities (or the elite) [131]. In my study, panic is seen as an intense emotionally charged group response to some external menace, actual or imagined. In many ways, when referring to panic in my thesis, I am adopting the popular view of a “high anxiety” or “primitive fear” that enables blind spots in ways that other emotions are not [135], largely to allow me to interpret and comment on this folk terminology that the majority of my included literature is actually adopting.
- Regret: unpleasant feeling following the perception that one has taken the wrong course of action [136].
- Shame: painful self-conscious feeling in which one perceives themselves to be defective, often in response to a perceived failure; sometimes may follow stigma and generally accepted moral values of majority culture [115, 137].
- Stress: anxiety or physical response to pressures from an event or ‘stressor’, especially in relation to experiencing something new or unexpected, something that threatens our competence/ego, and a feeling of little control over a situation [138].
- Worry: anxiety, especially in response to perceived susceptibility [139].

Eligibility criteria

The following criteria were used to identify studies eligible for inclusion in the review:

- Study design: All primary observational research studies, including cross-sectional and cohort studies, and randomised controlled trials. Modelling and statistical framework studies were excluded.
- Condition or domain studied: Infectious diseases with the capacity to cause outbreaks, epidemics or pandemics.
- Setting: Occurrences of infectious outbreaks, worldwide.

- Time frame: 1988-2019 (starting date chosen as the last major update to Health Belief Model, a dominant approach to assessing people’s capacity to act following risk communication). The last date of search was 23 May 2019.
- Language: Global, no limits (translation was sought where necessary).
- Publication status: Articles, reports or protocols published or publicised ahead of print.

A Population, Intervention, Comparison, Outcome (PICO) framework approach was used, wherein Participants were populations exposed to an infectious disease outbreak. Interventions were public health campaigns or healthcare-led communication of risk of an epidemic. Comparators were not applicable, and the Outcome was uptake of interventions (for example, vaccination).

Out of scope for inclusion were studies:

- assessing healthcare workers' perceptions (only studies on the general public were included);
- using a randomised controlled trial or any other experimental study design which was specifically looking at participation in a trial or study as an outcome (the review only covered real world scenarios);
- specifically examining perceptions/emotions towards a vaccine or other interventions (not towards an infectious disease or the reaction in relation to perception of risk of epidemic);
- looking at routine vaccinations (not focused on emergency settings);
- studying diagnosed psychiatric conditions, including health anxiety, (not emotions) and their relation to attitudes;
- examining responses of people already infected or exposed to the disease.

Information sources

The following bibliographical databases were accessed using the specified routes:

- PubMed/MEDLINE: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to May 23, 2019.

- Embase: through Ovid, Embase 1974 to May 23, 2019.
- PsycINFO: through Ovid, PsycINFO 1806 to May Week 3, 2019.
- CINAHL: EBSCOhost CINAHL Plus with Full Text.
- Global Health: through Ovid, Global Health 1910 to 2019, Week 20.

Further hand searches with some limited key terms were conducted in secondary research databases (for example, Cochrane Library, Epistemonikos) to cross-reference sources, and in grey literature sources (for example, OpenGrey). A consultation with expert sources, including colleagues from the London School of Hygiene & Tropical Medicine (LSHTM) Vaccine Confidence Project, further ensured that key studies were not missed.

Search strategy

A librarian from the LSHTM Library and Archives Services peer reviewed (May 2019) this systematic review's search strategy.

Search terms included variations of the following:

- emotion* OR panic* OR fear* OR afraid OR anxiet* OR anger* OR psychosomatic OR stress* OR empath* AND
- outbreak* OR epidemic* OR pandemic* OR infectio* OR ebola OR zika OR flu OR influenza AND
- perception OR perceive* OR risk* OR uncertain* OR associative thinking OR social contagion AND
- vaccin* or immuni#* or public health or preparedness or surveillance.

The full search strategy for Medline is provided in Table 3.1.

Key terms used for hand searches included: mass psychosomatic illness, immunisation stress related symptoms, emotional contagion, social contagion, associative thinking, risk amplification, mass drug administration, mass vaccination.

Table 3.1. Systematic review: Full search algorithmic strategy for Medline.		
Database(s): Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to May 23, 2019		
#	Searches	Results
1	exp Emotions/	225,239
2	(emotion* or panic* or fear* or afraid or anxiet* or anger* or psychosomatic or stress* or empath*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1,331,049
3	1 or 2	1,372,411
4	exp Disease Outbreaks/	89,061
5	exp Communicable Diseases/	33,802
6	exp Hemorrhagic Fevers, Viral/	25,722
7	exp Arbovirus Infections/	39,099
8	exp Influenza, Human/	46,481
9	(outbreak* or epidemic* or pandemic* or infectio* or ebola or zika or flu or influenza).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	2,089,454
10	4 or 5 or 6 or 7 or 8 or 9	2,113,665
11	exp risk/	1,126,968
12	exp Mental Processes/	981,803
13	(perception or perceive* or risk* or uncertain* or associative thinking or social contagion).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	2,971,053
14	11 or 12 or 13	3,661,895
15	exp Preventive Medicine/	34,862
16	exp Public Health Surveillance/	2,530

17	exp Communicable Disease Control/	322,914
18	exp Vaccination/	80,157
19	exp Preventive Health Services/	565,047
20	(vaccin* or immuni#* or public health or preparedness or surveillance).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	1,108,664
21	15 or 16 or 17 or 18 or 19 or 20	1,696,835
22	3 and 10 and 14 and 21	3,980
23	limit 22 to yr="1988 -Current"	3,868

Study selection and data extraction

The articles retrieved from the online searches were entered into an EndNote Library where duplicates were automatically and manually removed. The titles and abstracts of remaining articles were screened for the eligibility criteria by the lead researcher. After this, the full text articles were read and screened against the set criteria. From the identified relevant articles, data were extracted using a standardised form. These extracted data contained the following information: first author surname, year of publication, study design, region (including nation and continent) where the study was conducted, population (including size, percentage of women participants, and information on special subgroups), infectious disease studied, emotions studied, outcomes studied, and evidence of correlations. Emotions were studied in the context of being used in public health risk communications (that is, reported through the communication used) or, intentionally or unintentionally, evoked by such messaging (that is, reported or observed in the population studied). Additional information was extracted where deemed necessary narratively describing key conclusions or notes of the included articles. If any critical information was missing, study corresponding authors were contacted.

Strategy for data synthesis

A descriptive narrative approach was largely followed in the synthesis of the findings. Continuous variables were expressed as non-weighted means where possible. A narrative summary was produced per determinant linking information about the targeted population,

study design, type of outcome, determinant and correlations. Sub-analyses were explored for different regions/continents, different infectious diseases, different study designs (including data collection method), and special subgroups.

The variables that could be defined as categorical binary variables (for example, emotion evoked in a study or not) were included in a table. A meta-analysis was not designed because large variations were expected in the way determinants were captured and measured. Individual or community-level data were not pooled due to large differences in study designs and reported effect measures. However, some basic quantitative calculations were conducted. Binomial tests were performed using the direction of effect observed in each study as the outcome variable, that is, either favouring or not favouring intervention uptake. Binomial tests are used to test whether the probability of occurrence of one of two possible outcomes are different from a theoretical distribution of the data. In other words, I looked at the number of positive or negative correlations (correlations defined as the studies which reported that an emotion evoked served as a motivator for action in the population studied) for the number of studies involved. Where this number was statistically significantly greater than what would be expected for a regular binomial draw, I interpreted it as evidence to believe that this is not due to chance. Hence, I performed binomial tests against a test proportion of 0.5 or 50% for each study outcome. A two-sided p-value of < 0.05 was considered significant. All analyses were undertaken with STATA 16 (StataCorp, College Station, TX, USA).

Risk of bias in individual studies

A risk of bias assessment was conducted on the included studies. However, there are very few critical appraisal tools that have been designed specifically for use in public health practice. Most, draw their evidence from the principles of evidence based clinical medicine and follow the traditional hierarchies of study design and evidence levels [140]. In public health the evidence base tends to be highly heterogeneous, thus requiring a quality appraisal tool that can be generic and flexible to have utility for a wide range of projects across different topic areas [141]. Hence, since this has been exactly the case in my systematic review as well, I decided to use the Meta Quality Appraisal Tool (MetaQAT) which is a tool that accommodates several study designs relevant to public health and has been pilot tested and validated in similar studies [142]. MetaQAT has a meta-tool structure that provides one common appraisal process via a four-part framework covering: relevance, reliability, validity, and applicability [141]. A summary of the tool questions is provided in Table 3.2.

Similarly to the other steps of the systematic review, the quality appraisal was conducted by a single reviewer.

Since the aim remained to maximise the included articles so evidence can be drawn from all available diverse sources, the results of the assessment were not used to exclude articles. For each included study an answer was recorded on each question of the tool and the “yes”, “no”, “unclear” or “n/a” checkbox that accompanied each answer was ticked accordingly. The MetaQAT does not provide a numerical score for rating articles; rather, long-form responses recorded the identified strengths and weakness of each literature source [141, 143]. However, I did use the proportion of the various responses from the checkboxes to conduct sensitivity analyses. Even though the intention of the MetaQAT tool is not to provide a single numerical score for the quality of each study, using a recent adaptation of the tool [144], responses from the checkboxes were weighted and studies were assessed as of “high” (overall score more than 80%), “medium” (between 50% and 79%) or “low” (less than 50%) quality. Then, all statistical analyses in the review were conducted again in two ways: limited to the studies of high quality, and limited to the studies of medium and high quality. For the purposes of this assessment, “unclear” and “n/a” responses were grouped in the same category as “no” responses.

Table 3.2. The MetaQAT form summary of questions	
Relevancy	Does the study address a topic relevant to the issue under investigation?
Reliability	Is the study presented clearly?
	Are the research methodology and results clearly described?
	Are ethics procedures described?
Validity	Is the study methodology appropriate for the scope of research?
	Is the research methodology free from bias?
	Are the authors' conclusions explicit and transparent?
	Can I be confident about the findings?
Applicability	Can the results be applied within the scope of public health?

Results

Eligible articles

The search strategy yielded 11,522 potentially relevant articles from five databases. A further five records were identified via hand search in other sources. A total of 8,188 records remained

for screening titles and abstracts after duplicates were removed. For a remaining 150 articles the full-text was studied, 75 of which were excluded based on the exclusion criteria. In all, 75 studies were included in this review (Table 3.3). A relevant flow chart was constructed to detail the number of papers retrieved and the steps undertaken (Figure 3.1).

The 75 included studies have been published across almost all years between 1988 and 2019, and conducted across 28 different nations (most commonly in China and Hong Kong N=16, United States N=13, The Netherlands N=6, Australia N=6) in all continents except Central and Latin America. The studies included a total of 85,248 participants, with a further five studies conducted as national campaign evaluations covering substantial proportions of the nations’ populations but not necessarily direct participants. Data on age groups and gender for the participants were scarce. For the studies where study design information is available, 54 used a cross-sectional design and 18 a cohort design, whilst a variety of research methods was reported; 23 studies used quantitative methods (most commonly surveys), 17 used qualitative (most often focus groups and interviews), and seven used a mixed method design. Baseline characteristics of the included studies are included in Table 3.3 which can be found at the end of this chapter.

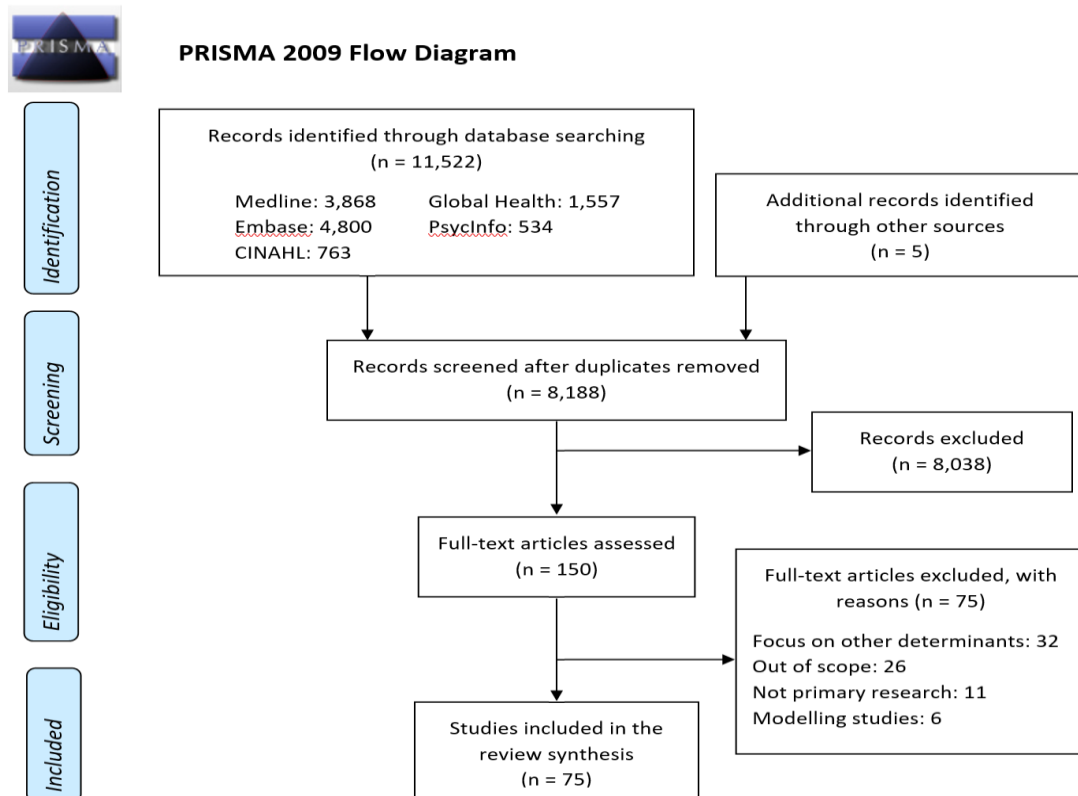


Figure 3.1. Flow chart of the database search steps.

Interventions and outcomes

Interventions to contain and respond to emerging epidemics covered a range of public health approaches and control measures. These included national campaigns, risk communication via media or social media, targeted education in the context of qualitative research settings, and more generally non-targeted media information about emerging epidemics.

Emotions were almost in all cases secondary study items or incidental findings. How outcomes were mentioned varied, but the ones included in this review (and, in particular, those feeding into the sub-analyses of high and medium quality studies) were those either correlated through statistical analyses, or clearly drawn from qualitative thematic analyses. The outcomes studied as potentially correlated with emotions were collected and categorised into seven groups. Those included:

1. Healthcare seeking behaviour (that is, to what extent participants would appropriately visit a doctor, hospital, or clinic to receive support or medication for symptoms).
2. Personal diagnostic testing (for infection).
3. Increased knowledge (about the infectious outbreak and appropriate action to take).
4. Further personal education (that is, the extent to which people got motivated to further study or find information about the infection).
5. Personal prophylactic measures (including condom use, face masks, handwashing and personal hygiene).
6. Other prophylactic measures (for example, compliance with quarantine, food hygiene methods, reduced travel, and avoiding crowded places).
7. Vaccination (only in scope in cases of infections for which immunisations were available).

Emotions

The 75 eligible studies attempted a total of 97 correlations between 12 emotions and the seven outcome groups. In almost all cases the statistical significance of these correlations was not reported, hence associations were recorded in this review as either positive or negative/non-existent. The 12 emotions identified and their classifications are listed in Table 3.4. The word

cloud in Figure 3.2 presents the 12 emotions with the size of the words weighted for how frequently they were studied.

Table 3.4. Emotions studied in the included papers of the review.

Unpleasant emotions		Pleasant emotions	Intense / extreme unpleasant emotions	Anxiety-related (moderate) emotions
Fear	Stress	Empathy	Fear	Anxiety
Anxiety	Concern	Hope	Panic	Worry
Worry	Hopelessness		Hopelessness	Stress
Panic	Regret		Shame	Concern
Apathy	Shame			

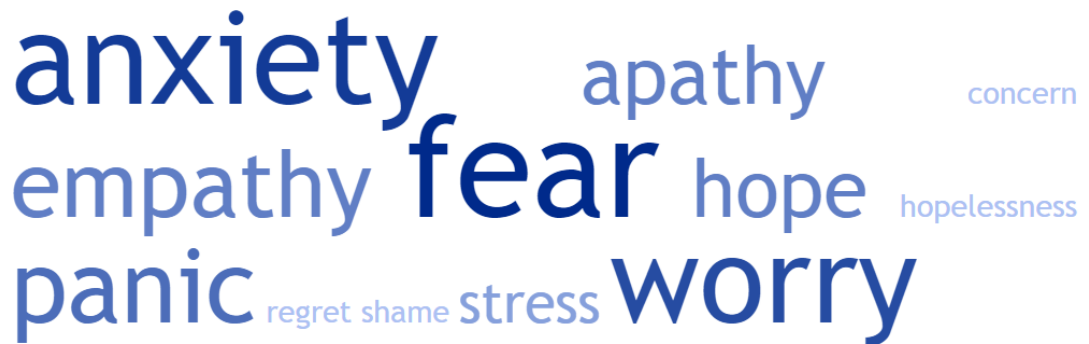


Figure 3.2. Word cloud of emotions studied in the review, weighted by frequency.

Unpleasant emotions were evoked much more often than pleasant in response to public health risk communications. Fear was the most commonly evoked emotion in the included studies, followed by anxiety, worry and panic. Empathy and hope were the pleasant emotions studied in the included papers.

Analyses

There was evidence that the emotions of fear and panic had a negative effect on the uptake of public health interventions during the outbreaks studied with 23 out of 27 studies and 10 out of 10 respectively showing a lack of action on uptake of interventions (p<0.001 and p=0.002

respectively). On the contrary, the emotions of worry (17 out of 17 studies, $p < 0.001$) and empathy (6 out of 6 studies, $p = 0.031$) emerged as the key motivators for action. Overall, moderate anxiety-related emotions (worry, anxiety, stress, concern) seemed to be much more significant motivators for action for the public compared to extreme unpleasant emotions (fear, panic, hopelessness, shame) which very rarely led to an outcome (10% of the studies, $p < 0.001$).

The correlations between emotions and outcomes are summarised in Table 3.5.

A total of 10 different types of infections were studied in the included papers. The word cloud in Figure 3.3 presents these 10 infections with the size of the words weighted for how frequently they were studied.



Figure 3.3. Word cloud of infections studied in the review, weighted by frequency.

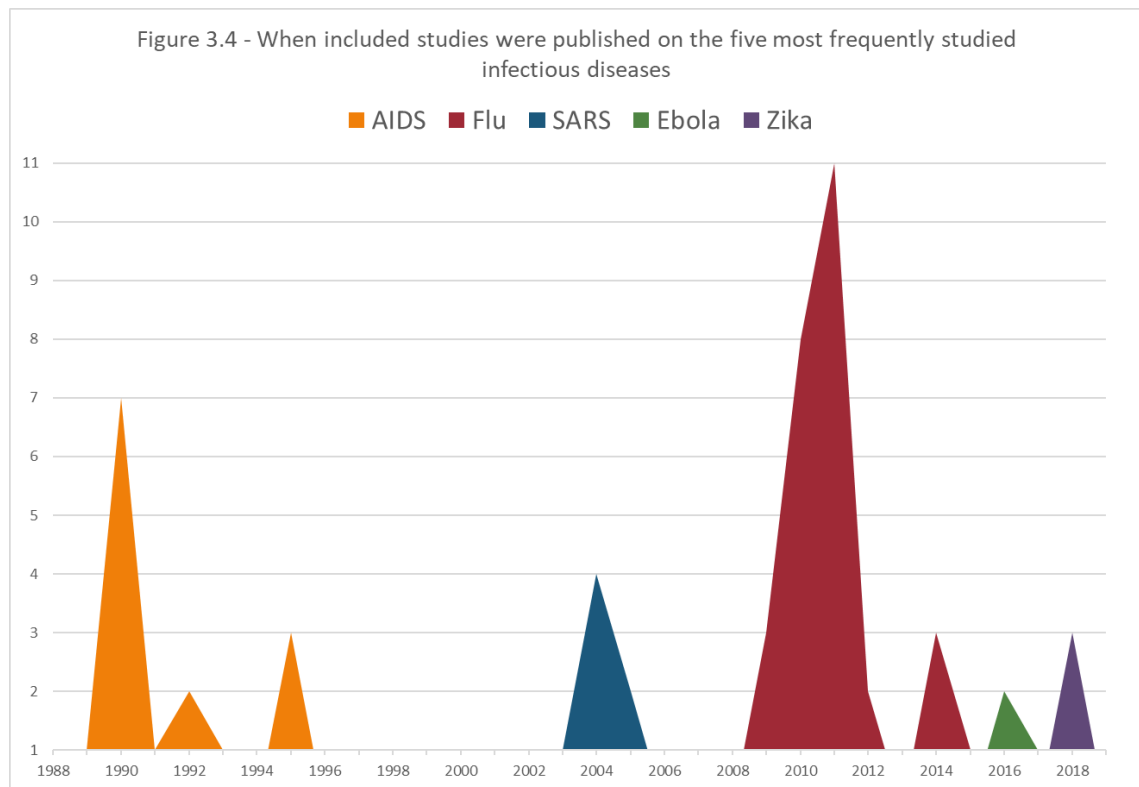
Table 3.5. Emotional determinants studied in the included papers.

	Emotions	Correlations attempted	Proportion favouring intervention	95% confidence interval for the proportion	p-value, two sided (* significance)
1	Fear x^	29	15%	1% - 34%	0.008 *
2	Anxiety x#	23	65%	43% - 84%	0.210
3	Worry x#	17	100%	81% - 100%	< 0.001 *
4	Panic x^	10	0%	0% - 31%	0.002 *
5	Empathy §	6	100%	54% - 100%	0.031 *
6	Apathy x	4	0%	0% - 60%	0.125
7	Hope §	4	50%	1% - 93%	1.000
8	Stress x#	2	100%	16% - 100%	0.500
9	Concern x#	1	100%	1% - 100%	1.000
10	Hopelessness x^	1	0%	0% - 98%	1.000
11	Regret x	1	100%	1% - 100%	1.000
12	Shame x^	1	0%	0% - 98%	1.000
	xUnpleasant emotions	89	46%	35% - 57%	0.520
	§ Pleasant emotions	10	80%	44% - 97%	0.109
	^ Extreme unpleasant emotions	41	10%	1% - 24%	< 0.001 *
	# Anxiety-related emotions	43	81%	67% - 91%	< 0.001 *

“Correlations attempted” means how many associations were observed between an emotion and an outcome in the included studies, and, hence, may be higher than number of studies.

“Proportion favouring intervention” means the proportion of studies in which a positive effect on intervention uptake was observed.

Most research on infectious diseases was usually published around or following the years of outbreaks in specific regions (Figure 3.4).



Influenza was the most common (N=40), with A/H1N1 the most common subtype (in 84% of influenza studies, predominantly A/H1N1-pdm09), and most research published between 2009-2011, followed by Human Immuno-Deficiency Virus / Acquired Immuno-Deficiency Syndrome (HIV/AIDS) (N=26), with the bulk of the research between 1988-1998. Twelve correlations were recorded for Severe Acute Respiratory Syndrome (SARS), with the majority of studies focusing on anxiety and fear from Singapore and Hong Kong between the years of 2003 and 2005. For Ebola, most studies were conducted in African countries between the years of 2016-2017, and there were also four recent studies on Zika.

Any other statistically significant correlations are included in Table 3.6.

Table 3.6. The most significant contributions of emotional determinants studied in the included papers.

Domain	Emotional determinants	Correlations attempted	Proportion leading to outcome	p-value, two sided (*significance)
AIDS	Unpleasant emotions	24	29%	0.063
	Extreme emotions	19	21%	0.019 *
Ebola	Extreme emotions	6	0%	0.031 *
Influenza	Moderate emotions	28	79%	0.004 *
SARS	Unpleasant emotions	8	88%	0.070
	Moderate emotions	6	100%	0.031 *
Direct contact transmitted infections	Extreme emotions	27	19%	< 0.001 *
	Moderate emotions	12	83%	0.039 *
African nations	Unpleasant emotions	11	0%	< 0.001 *
	Extreme emotions	11	0%	< 0.001 *
Asian nations	Extreme emotions	12	17%	0.038 *
European nations	Moderate emotions	14	86%	0.013 *
	Unpleasant emotions	20	75%	0.041 *
North American nations	Extreme emotions	11	18%	0.065
Adolescents	Moderate emotions	7	100%	0.015 *

“Outcome” means an observed increase in the uptake of interventions.

For reasons of brevity: “extreme emotions” are “extreme unpleasant emotions”, “moderate emotions” are “anxiety-related emotions”.

Extreme unpleasant emotions had a statistically significantly negative effect on the uptake of public health interventions in several cases: in HIV/AIDS, in direct contact transmitted infections (AIDS, Ebola, MERS CoV, SARS), in studies conducted in African and Asian nations. Anxiety-related emotions were the key motivator for action in the case of influenza and SARS, were studied much more commonly in European studies, whereas in all African studies only extreme unpleasant emotions were studied with 11 out of 11 studies showing a lack of action on uptake of interventions ($p < 0.001$).

For HIV/AIDS, the association between evoking an emotion of fear and uptake of testing for the condition was studied most often ($N=6$). A correlation to a positive outcome was recorded in just 29% of studies, significant at 90% ($p=0.063$). For influenza, anxiety was the most common emotion evoked, emerging, along with other moderate determinants, consistently as a key motivator for action. Fear was evoked in most studies in the case of Ebola, but had a negative effect on the uptake of public health interventions with none of the studies showing a positive effect on uptake (zero out of six studies, $p=0.031$). Evoking anxiety-related emotions was significantly correlated to the uptake of interventions for SARS ($N=6$, $p=0.031$).

When assessed at a more granular level, by country or specific region, groupings were generally too small for statistical significance, though the overall trends were similar to the above observations (moderate emotions much more frequently correlated to an outcome than extreme unpleasant emotions, and pleasant emotions most often associated with action on the uptake of interventions). Further sensitivity analyses were conducted for special sub-groups studied in the included papers. Special groups included adolescent and young adults, black minority communities, Lesbian, Gay, Bisexual, Trans and other sexuality identities (LGBT+) people, people with long-term conditions, high risk and pregnant women but any trends were too small for statistical significance.

Study design did not seem to significantly influence the results, though in many more cases a cross-sectional design (N=71) was used than a cohort (N=23). Of note, all research studying pleasant emotions followed a cross-sectional design, with a variety of qualitative methods (for example, surveys, interviews, and focus groups).

Risk of bias analysis

The overall risk of bias of the included studies was low to medium. Out of the 75 included studies, 68% (N=51) were deemed as of high quality (low risk of bias), 25% (N=19) of medium quality, and 7% (N=5) of low quality (high risk of bias). However, for almost a third (N=23) of the included studies ethical procedures were not described (or was unclear whether they had been followed) and for almost a third (N=24) it was not possible to conclude if the methodology was completely free of bias. In some cases these were due to the potential for recall and social desirability bias due to the cross-sectional nature surveys, whilst in others potential sources of bias included small or non-representative sample sizes.

All significant correlations for emotions, as outlined in Table 3.5, remained significant when limited to the medium and high quality studies in the sensitivity sub-analyses, except for the correlation between empathy and uptake of interventions when limited only to high quality studies (Table 3.7).

Table 3.7. Analyses limited to the high and medium quality studies, for the significant correlations of the baseline analyses.

Emotions	All studies		“High” quality studies		“High” and “medium” quality studies	
	Correlations	p-value, two sided, as in Table 3.4	Proportion of correlations	p-value, high quality	Proportion of correlations	p-value, high & medium quality
Fear	29	0.008 *	20/29	0.041 *	27/29	0.019 *
Worry	17	< 0.001 *	14/17	< 0.001 *	17/17	< 0.001 *
Panic	10	0.002 *	7/10	0.015 *	8/10	0.008 *
Empathy	6	0.031 *	5/6	0.062	6/6	0.031 *
Extreme emotions	39	< 0.001 *	27/41	0.002 *	37/41	< 0.001 *
Moderate emotions	43	< 0.001 *	31/43	< 0.001 *	41/43	< 0.001 *

* significance

“Extreme emotions” are extreme unpleasant emotions; “Moderate emotions” are anxiety-related emotions.

Discussion

A detailed in-depth discussion of themes and the literature is included in a separate chapter in my thesis. Here, I am discussing the key findings and limitations of the literature review.

Summary of findings

Unpleasant emotions were evoked much more often than pleasant following public health risk communications, with fear and anxiety being the most common. Influenza and AIDS were the most frequently studied infections, but overall, there were clear surges in the literature on infections studied in the years following first emergence or major outbreaks. Key findings of my review are summarised in Table 3.8. All significant correlations largely maintained their significance when limited to the high and medium quality studies.

There was evidence that the emotions of *fear* and *panic* had a negative effect on the uptake of public health interventions during the outbreaks studied, whereas *worry* and *empathy* emerged

as the key motivators for action. Overall, moderate anxiety-related emotions (worry, anxiety, stress, concern) seemed to be much more significant motivators for action for the public compared to extreme unpleasant emotions (fear, panic, hopelessness, shame) which had a statistically significantly negative effect on the uptake of public health interventions in several cases.

The strongest finding of this review was the strong negative correlation between extreme unpleasant emotions and uptake of public health interventions. None of the emotions defined as extreme (fear, panic, hopelessness, shame) seemed to point towards delivering any outcomes. Of note, in none of the cases where panic was evoked as an emotion did action (in the form of uptake of an intervention) follow.

Unpleasant emotions were used much more often than pleasant in public health risk communications. However, despite the fact that few studies have researched how pleasant emotions may lead to positive outcomes in epidemics, the trend was strong with eight out of 10 occurrences leading to uptake of interventions. More research will be needed to confirm this trend. Empathy and hope were the two pleasant emotions studied.

Table 3.8. Key findings of my review
<p>In relation to the uptake of public health interventions:</p> <ul style="list-style-type: none"> • Fear and panic had a negative effect. • Moderate anxiety-related emotions (worry, anxiety, stress, concern) were significant motivators for action. • There was a lack of correlation for extreme unpleasant emotions. • Empathy had a positive effect.

Moderate anxiety-related emotions covering concepts largely synonymous with “feeling concerned or anxious”, were also strongly correlated with uptake of interventions in this review, clearly pointing to a direction for how the public can be motivated to take action in response to the risk of an epidemic. This was also the case when targeting adolescents and young adults.

Despite the included papers covering a range of nations and continents, in the case of studies in African nations (largely focused on Ebola) only extreme unpleasant emotions were assessed, with a complete lack of associations to outcomes. There were no relevant studies conducted in

Central and Latin America, although a recent study has assessed the role of hope and trust amongst healthcare workers [134].

Limitations

This review identified some anticipated limitations: emotions were never the primary variable in the included studies, quantitative data were scarce, it was only rarely reported where certain emotional determinants were counterproductive to an outcome, and the actual definitions of emotions in the included studies were far from systematic and consistent. For example, one study simply asked a sample of university students to rate their concern about the risk of the H1N1 pandemic on the basis of a simple rating scale where the options were: “*not worried at all, worried, very worried*”. However, the paper then went on to talk about “*fear*” of the pandemic and attitudes [145]. Another study used two simple scales to assess the level of fear (from: “*not at all afraid (0) to very afraid (4)*”), and worries about personal and family safety (from: “*not worried at all (0) to very worried (3)*”), but then grouped the two results into a single concept of “*fear/worry*” [146]. In another study the emotional state of participants was included into their beliefs and the Health Belief Model was used [147].

Furthermore, the outcome in the studies (intervention uptake) was studied in a dichotomous way (yes or no), and no effect sizes were available. Hence, for the data synthesis, some very diverse data were pooled and the analysis conducted seems to have been all that was feasible given the significant heterogeneity between studies and what was reported. To address this limitation using a systematic method, I looked at the number of positive or negative correlations (correlations defined as the studies which reported that an emotion evoked served as a motivator for action in the population studied) for the number of studies involved. Where this number was statistically significantly greater than what I would expect for a regular binomial draw, I interpreted it as evidence to believe that this is not due to chance. Of course, a number of assumptions (mostly due to the heterogeneity of the data) had to be made, and the wider thesis remains a highly narrative piece of work, so this is an attempt to quantify some of the available evidence so that some conclusions based on pooled data could be made.

In addition, effect sizes were not recorded in the included studies for the variables and outcomes studied and individual participant data were not assessed, however, the review derived its evidence from a total overall sample of more than 80,000 subjects across a variety of nations, continents and contexts. An important limitation of the review is the narrow assessment of emotions and outcomes in the included studies, which fails to capture the depth and breadth of

the human experience in response to outbreaks. This can only be addressed by a more in depth study of outbreaks as they occur in local regions.

Next steps

This is the first review of its kind studying the role of emotional determinants and it shows that emotions are an important lever in determining health decisions. The public's emotional responses to epidemics in the past 30 years have played a clear role in determining how successful public health interventions have been. Given identified differences between pleasant and unpleasant, moderate (anxiety-related) and extreme emotions, and some variability by infection, outcome and region, a nuanced understanding of how emotional determinants determine public responses and health outcomes at a local level is needed.

In the next chapter, I present a detailed review of each of the five most frequently studied infectious disease outbreaks as experienced in specific nations, from a range of periods in the same timeframe as the review (Figure 3.5). This will provide the depth that is much needed in assessing how emotions interact with the local contextual factors to influence the responses of the public and, hence, inform how public health communications can work to take these into account. The geographical regions, by nation, that were studied in the review and the added case studies are shown in Figure 3.6. The five national case studies have been chosen for a few reasons, namely to expand the evidence collected in this study in a variety of geographical regions, and to include study of settings with recent memories of crises where the emotional collective consciousness is enough to draw meaningful conclusions.

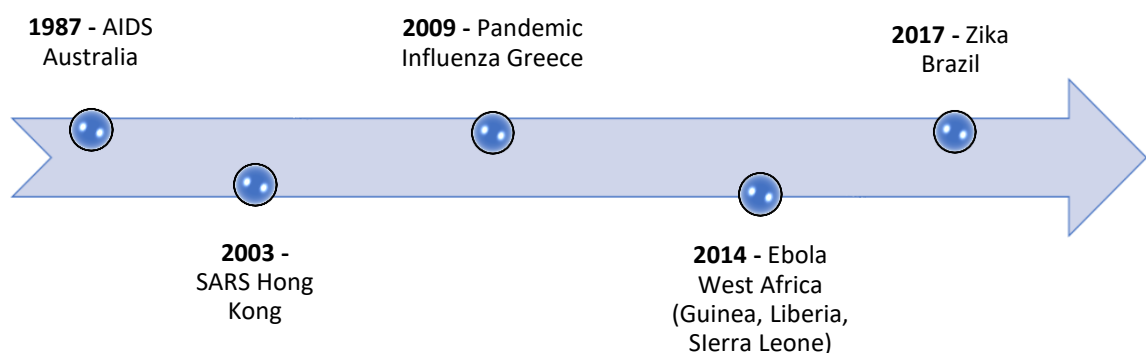


Figure 3.5. *The outbreaks that studied in depth.*

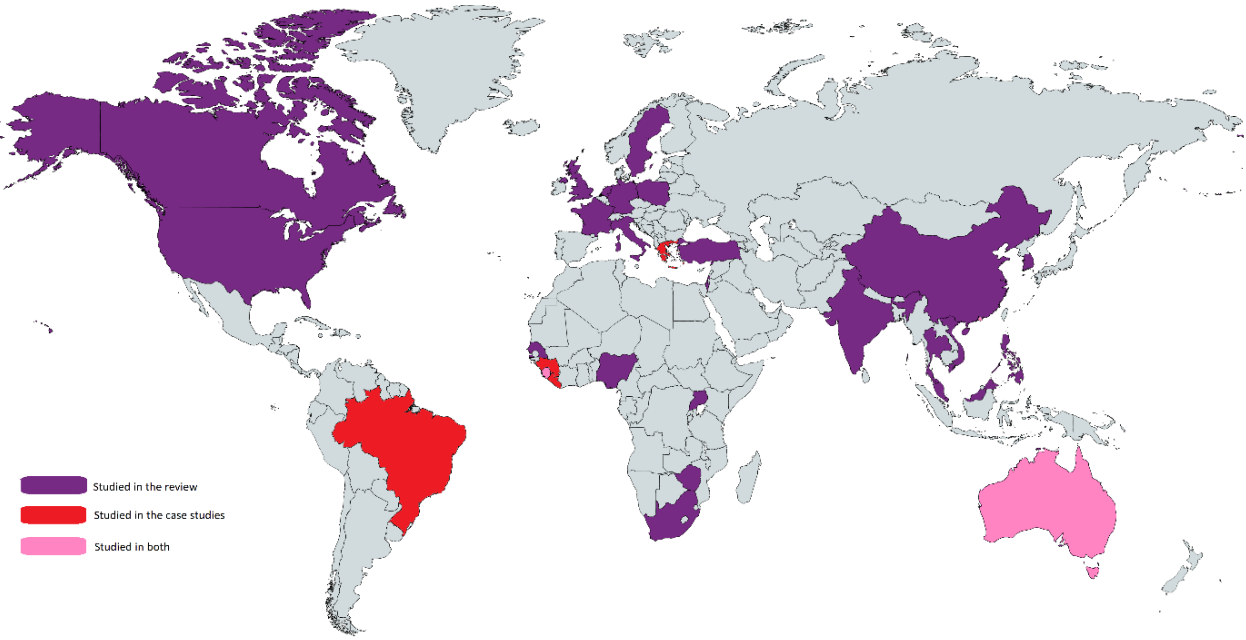


Figure 3.6. Map of countries studied in the thesis.

Table 3.3. Summary of included studies in the review.

First Author Surname & Citation	Pub. Year	Study type		Region			Population		Infection studied	Emotions studied	Outcomes studied (uptake of public health interventions)
		Approach	Method	Area	Country	Cont.	Size	Special groups studied			
Morlet [148]	1988	Campaign evaluation	Cohort	Sydney	Australia	Oceania	3.5m	Gay men*	AIDS	Fear	Testing
Nutbeam [149]	1989	Survey	Cross-sectional	N/A	Wales	Europe	1,303	N/A	AIDS	Anxiety	Knowledge
Berkley [150]	1990	Survey	Cross-sectional	N/A	Uganda	Africa	1,300	Women	AIDS	Fear	Other prophylactic measures
Eddings [151]	1990	Campaign evaluation	Cohort	Soweto, Johannesburg	South Africa	Africa	750k	Black people*	AIDS	Fear	Knowledge
Herlitz [152]	1990	Survey	Cross-sectional	N/A	Sweden	Europe	1,630	Police officers, public, 25-44y.o.	AIDS	Fear	Advocacy for measures
Kozak [153]	1990	Survey	Cross-sectional	N/A	Poland	Europe	1,402	N/A	AIDS	Apathy	Personal prophylactic measures
Marshall [154]	1990	Survey	Cross-sectional	N/A	United States	North America	350	N/A	AIDS	Fear	Knowledge, Testing

Petosa [155]	1990	N/A	N/A	South Carolina	United States	North America	N/A	Adolescents	AIDS	Fear	Knowledge
Rhodes [156]	1990	Campaign evaluation	Cohort	California	United States	North America	261	College students*	AIDS	Fear	Personal prophylactic measures
Williams [157]	1991	Interviews	Cross-sectional	N/A	United States	North America	21	High risk women	AIDS	Hope	Personal prophylactic measures
Lupton [158]	1992	Campaign evaluation	Cohort	N/A	Australia	Oceania	16.5m	N/A	AIDS	Panic	Knowledge
Moatti [159]	1992	Campaign evaluation	Cross-sectional	N/A	France	Europe	1,000	N/A	AIDS	Empathy	Personal prophylactic measures
Ramsum [160]	1993	Survey	Cohort	British Columbia	Canada	North America	493	College students	AIDS	Fear	Personal prophylactic measures
Ames [161]	1995	Survey	Cross-sectional	N/A	United States	North America	280	Gay men	AIDS	Fear	Personal prophylactic measures
Richard [162]	1995	Survey	Cross-sectional	N/A	Netherlands	Europe	N/A	Adolescents	AIDS	Worry, Regret	Personal prophylactic measures

Sweat [163]	1995	Interviews & focus groups	Cohort	N/A	Thailand	Asia	834	Men in military	AIDS	Fear	Knowledge
Samet [164]	1997	Survey	Cross-sectional	Massachusetts	United States	North America	567	Adolescents	AIDS	Worry	Testing
Bockting [165]	1998	Focus groups	Cross-sectional	N/A	United States	North America	19	Trans people	AIDS	Shame, Fear, Hopelessness	Personal prophylactic measures
Griffin [166]	1998	Survey	Cross-sectional	Milwaukee	United States	North America	610	N/A	Cryptosporidiosis	Worry	Further personal education
Laver [167]	2001	Survey	Cross-sectional	Mashonaland	Zimbabwe	Africa	204	N/A	AIDS	Fear	Testing
Lau [168]	2003	Survey	Cohort	Hong Kong	China	Asia	1,397	18-60y.o.	SARS	Fear	Personal prophylactic measures
Brug [169]	2004	Survey	Cross-sectional	N/A	Netherlands	Europe	373	19-78y.o.	SARS	Worry	Personal prophylactic measures
Leung [170]	2004	Survey	Cross-sectional	Hong Kong	China	Asia	705	N/A	SARS	Anxiety	Other prophylactic measures
Quah [171]	2004	Survey	Cross-sectional	N/A	Singapore	Asia	1,201	N/A	SARS	Anxiety	Other prophylactic measures

Lee-Baggley [172]	2004	Survey	Cross-sectional	N/A	Canada * International	North America	73	N/A	SARS	Empathy, Hope	Other prophylactic measures
Cava [173]	2005	Interviews	Cross-sectional	Toronto	Canada	North America	21	N/A	SARS	Worry	Other prophylactic measures
Lau [174]	2005	Survey	Cross-sectional	Hong Kong	China	Asia	1,681	N/A	SARS	Panic	Healthcare seeking behaviour
Leung [175]	2005	Survey	Cohort	Hong Kong	China	Asia	4,481	N/A	SARS	Anxiety	Personal prophylactic measures
Lau [176]	2007	Survey	Cross-sectional	Hong Kong	China	Asia	805	N/A	H5N1 Flu	Panic	Personal prophylactic measures
Tian [177]	2007	Survey	Cross-sectional	Hangzhou	China	Asia	2,424	N/A	SARS	Stress	Personal prophylactic measures
Goodwin [178]	2009	Survey	Cross-sectional	N/A	Malaysia	Asia	180	N/A	H1N1 Flu	Anxiety	Other prophylactic measures
				N/A	N/A	Europe	158	N/A	H1N1 Flu	Anxiety	Other prophylactic measures
Rubin [179]	2009	Interviews	Cross-sectional	N/A	United Kingdom	Europe	1,000	N/A	H1N1 Flu	Anxiety	Other prophylactic measures

Puterman [180]	2009	Survey	Cross-sectional	N/A	Canada * International	North America	238	N/A	SARS	Empathy, Hope	Other prophylactic measures
		Survey	Cross-sectional	N/A	Canada * International	North America	190	N/A	West Nile Virus	Empathy, Hope	Other prophylactic measures
Bults [181]	2010	Survey	Cross-sectional	N/A	Netherlands	Europe	754	N/A	H1N1 Flu	Anxiety	Personal prophylactic measures
Cowling [182]	2010	Survey	Cohort	Hong Kong	China	Asia	12,965	N/A	H1N1 Flu	Anxiety, Worry	Personal prophylactic measures
Eastwood [183]	2010	Survey	Cohort	N/A	Australia	Oceania	830	N/A	H1N1 Flu	Concern	Personal prophylactic measures
Hutchinson [184]	2010	Interviews	Cross-sectional	Melbourne	Australia	Asia	80	COPD patients	H1N1 Flu	Anxiety	Knowledge
Lau [185]	2010 a	Survey	Cross-sectional	Hong Kong	China	Asia	999	N/A	H1N1 Flu	Stress	Personal prophylactic measures
Lau [186]	2010 b							N/A		Panic	Other prophylactic measures
Leung [187]	2010	Interviews	Cross-sectional	Hong Kong	China	Asia	278	Rheumatic patients	H1N1 Flu	Fear	Vaccination
Setbon [188]	2010	Interviews	Cross-sectional	N/A	France	Europe	1,001	N/A	H1N1 Flu	Worry	Vaccination

Van [189]	2010	Survey	Cross-sectional	Sydney	Australia	Oceania	2,882	University setting	H1N1 Flu	Anxiety, Apathy	Vaccination
Bults [190]	2011	Survey	Cohort	N/A	Netherlands	Europe	934	N/A	H1N1 Flu	Anxiety	Personal/Other prophylactic measures
Cirakoglu [191]	2011	Survey	Cross-sectional	N/A	Turkey	Europe/Asia	697	University students*	H1N1 Flu	Anxiety	Other prophylactic measures
Ferrante [192]	2011	Survey	Cross-sectional	N/A	Italy	Europe	4,047	N/A	H1N1 Flu	Worry	Vaccination
Kanadiya [193]	2011	Survey	Cross-sectional	N/A	United States	North America	236	College students	H1N1 Flu	Anxiety	Personal prophylactic measures
Liao [139]	2011	Survey	Cross-sectional	Hong Kong	China	Asia	1,760	N/A	H5N1 Flu	Worry	Personal prophylactic measures
Lin [194]	2011	Survey	Cross-sectional	N/A	China	Asia	10,669	N/A	H1N1 Flu	Worry	Vaccination
Serino [145]	2011	Survey	Cross-sectional	Rome	Italy	Europe	436	University students	H1N1 Flu	Worry	Vaccination, Personal prophylactic measures
Van der Weerd [146]	2011	Survey	Cohort	N/A	Netherlands	Europe	8,055	N/A	H1N1 Flu	Fear	Vaccination
Velan [195]	2011	Survey	Cross-sectional	N/A	Israel	Asia	501	N/A	H1N1 Flu	Fear	Vaccination

Li [196]	2011	Survey	Cohort	N/A	United States	North America	472	N/A	H1N1 Flu	Worry	Vaccination
Manabe [197]	2011	Survey	Cross-sectional	Bac Kan	Vietnam	Asia	543	N/A	H5N1 Flu	Panic	Healthcare seeking behaviour, Personal prophylactic measures
Marshall [198]	2012	Survey/ Campaign evaluation	Cohort	N/A	Australia	Oceania	1.5m	N/A	H1N1 Flu	Anxiety	Vaccination, Other prophylactic measures
Ashbaugh [147]	2012	Survey	Cross-sectional	N/A	Canada	North America	816	N/A	H1N1 Flu	Anxiety	Vaccination
Asogun [199]	2014	Focus groups	Cross-sectional	Edo State	Nigeria	Africa	15	N/A	Lassa Fever	Fear, Panic	Healthcare seeking behaviour
Bults [200]	2014	Survey	Cohort	N/A	Netherlands	Europe	1,030	N/A	Q fever	Anxiety, Apathy	Other prophylactic measures
Goodwin [201]	2014	Interviews	Cross-sectional	N/A	China	Asia	1,011	N/A	H7N9 Flu	Anxiety	Other prophylactic measures
Kim [202]	2014	Interviews	Cross-sectional	N/A	South Korea	Asia	3,462	N/A	H1N1 Flu	Anxiety	Vaccination, Other prophylactic measures

Lohiniva [203]	2014	Interviews & focus groups	Cross-sectional	N/A	Morocco	Africa	123	Pregnant women	H1N1 Flu	Fear, Panic	Vaccination
Bond [204]	2015	Interviews & focus groups	Cross-sectional	New York	United States	North America	116	Gay Black men	AIDS	Fear	Testing
Kwon [205]	2015	Campaign evaluation	Cohort	N/A	South Korea	Asia	50.7m	N/A	MERS CoV	Anxiety	Other prophylactic measures
Wu [206]	2015	Survey	Cross-sectional	N/A	China	Asia	540	Parents	H1N1 Flu	Fear	Vaccination
Ayegbusi [207]	2016	Interviews	Cross-sectional	Oyo State	Nigeria	Africa	25	Bush meat handlers	Ebola	Panic	Other prophylactic measures
King [208]	2016	Survey	Cross-sectional	Dharwad	India	Asia	100	N/A	H1N1 Flu	Empathy	Vaccination, Personal prophylactic measures
Lau [209]	2016	Survey	Cross-sectional	Guangzhou	China	Asia	1,155	University students	Ebola	Fear, Panic	Knowledge
Yamanis [210]	2016	Interviews	Cross-sectional	N/A	Sierra Leone	Africa	30	N/A	Ebola	Fear	Knowledge, Healthcare seeking behaviour

Desclaux [211]	2017	Interviews	Cross-sectional	N/A	Senegal	Africa	74	N/A	Ebola	Fear	Other prophylactic measures
de Lind van Wijngaarden [212]	2018	Interviews	Cross-sectional	Manila	Philippines	Asia	12	N/A	AIDS	Fear	Testing
Ludolph [213]	2018	Survey	Cross-sectional	Hong Kong	China	Asia	533	N/A	MERS CoV	Worry	Other prophylactic measures
Reyes-Medina [214]	2018	Survey	Cross-sectional	Puerto Rico	United States	Caribbean	158	N/A	Zika Virus	Worry, Apathy	Personal prophylactic measures
Obenauer [215]	2018 ^a	Survey	Cross-sectional	Saxony	Germany	Europe	1,063	N/A	Zika Virus	Fear	Other prophylactic measures
Obenauer [216]	2018 ^b	Survey	Cohort	Saxony	Germany	Europe	620	N/A	Ebola	Worry	Knowledge
Dillard [217]	2018	Survey	Cross-sectional	N/A	United States	North America	561	N/A	Zika Virus	Fear	Other prophylactic measures
Liao [218]	2019	Survey	Cohort	Hong Kong	China	Asia	464	N/A	H7N9 Flu	Worry	Other prophylactic measures

Acronyms: AIDS: Acquired Immuno-Deficiency Syndrome; MERS CoV: Middle East Respiratory Syndrome – related CoronaVirus; N/A: Not Available; SARS: Severe Acute Respiratory Syndrome.

CASE STUDIES

“Plagues are as certain as death and taxes.”

(Dr. Richard M. Krause)

Quoted in “Emerging infections”, by Morse SS (ed); Oxford University Press: Oxford, 1993.

4. CASE STUDIES

AIDS in Australia, 1980s

Context

Acquired Immune Deficiency Syndrome (AIDS), the spectrum of diseases caused due to infection by the Human Immunodeficiency Virus (HIV) was first reported among humans (as a result of earlier cross-species transmission) in the early 1980s [219]. It first attracted global attention when young, gay men in New York City and Los Angeles started developing rare opportunistic infections [220], though Simian Immunodeficiency Viruses (SIVs) had been identified among several primate species in west and sub-Saharan Africa [219] and evidence suggests that cross-species transmission of HIV-1 may have occurred in multiple transmission events during bushmeat hunting and handling [221]. Over a period of four decades AIDS has charted a unique course in the history of public health with widespread social, economic, demographic and political implications.

As treatments became more effective and widely available, and the natural history of the condition shifted from “people dying from” to “people living with”, preventative and care perspectives shifted a lot as well [222]. The unprecedented response at both a global and a local level gave rise to the notion of “AIDS exceptionalism”, that is, that the disease requires a response that goes over and above the usual public health interventions [223]. The exceptional responses, though, noticed in many countries were not necessarily positive, and the social history and legacy of AIDS is one that is closely intertwined with stigma, racism, activism and human rights issues [222].

In Australia, the first case of AIDS was recorded at St. Vincent’s Hospital in Darlinghurst, Sydney, in November 1982 [224]. The first death was reported a few months later, in July 1983 [225]. Earlier that same year, information about this new condition was first brought to the government’s attention; in March 1983, Neal Blewett, the Federal Health Minister, was handed a folder. The contents described Gay-Related Immune Deficiency (GRID) and noted that while the aetiology of the new disease was still unknown, gay men were primarily being affected [226]. As understanding of the condition increased, the acronym GRID was soon replaced with AIDS.

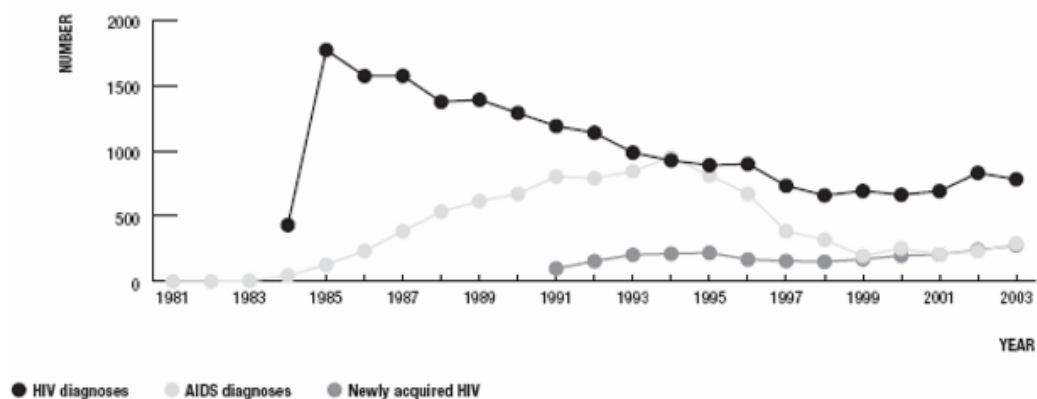
Despite increasing political mobilisation by affected community groups, the Australian government was initially slow to respond. In July 1984, however, Australia recorded its first case

of HIV infection linked to blood transfusion [220]. This case signalled risk of spreading beyond the gay community and spurred renewed interest in the disease. The Australian government, in collaboration with grassroots activist groups, enacted a concentrated, multi-faceted policy response throughout the 1980s. Through joint decision-making, the country’s innovative initiatives curbed incident infections as well as public stigma. While HIV infections continued to spread, Australia’s response largely kept the epidemic contained among the highest risk groups. Australia’s effective public health strategy, including the allocation of responsibilities across government sectors, is widely regarded as a model of best practice [220]. Here, the links of this to the emotional determinants of the pandemic are discussed.

Epidemiology

HIV is transmitted through bodily fluids including blood; semen or pre-seminal fluid; rectal or vaginal fluid; and breast milk. These fluids may enter the bloodstream through mucus membranes or open cuts during vaginal or anal sex, or through direct injection. While less common, HIV may also be transmitted from mother to child during pregnancy, birth, or breastfeeding. Abstinence, limiting the number of sexual partners, using condoms, and using sterile needles/syringes during injection drug use are the most effective methods of preventing HIV. Now, pre- and post-exposure prophylaxis (PrEP and PEP) are also used to prevent infection among individuals at high risk of exposure [227]. The direct contact – and crucially the sexual contact – transmission of HIV is closely linked with its social history.

1 HIV diagnoses adjusted for multiple reporting. AIDS diagnoses adjusted for reporting delays.



Source: National Centre in HIV Epidemiology and Clinical Research, 2004 Annual Report

Figure 4.1. Number of diagnoses of HIV infection and AIDS in Australia, 1981-2003

With limited treatment options, most HIV cases at the time would progress to AIDS and mortality was high. In Australia, by the end of 1984, 47 individuals had been diagnosed with AIDS and 18 had died [226]. However, contemporary analyses suggest that the annual number of incident cases of HIV in Australia peaked in 1984 [228] (Figure 4.1), with estimates saying that there were more than 10,000 cumulative cases of HIV by the end of 1987. Back projection techniques estimate $n=1,930$ new cases in 1983, $n=2,890$ in 1984, $n=2,630$ in 1985, $n=1,960$ in 1986, and $n=1,260$ in 1987 [225]. These numbers continued to drop through the rest of the 1980s and into the 1990s. Cases were largely identified among at-risk groups including overwhelmingly, men who have sex with men (MSM). Injection drug users (IDUs) and some recipients of blood products such as haemophiliacs were also at high risk [229]. In the early phase of the epidemic, HIV was largely contained within large cities; between 1983 and 1985, 4,500 MSM had been infected in Sydney and Melbourne [225].

A study of HIV antibody tests from 1984 to 1988 at a private Sexual Transmitted Diseases (STDs) clinic in Sydney found that 98.9% of seropositive tests were among MSM [230]. Of all 16,765 HIV cases reported in Australia between 1984 and 1992, 80% were attributable to male homosexual intercourse [231]. However, while the number of new cases decreased annually from 1985, the proportion of cases linked to heterosexual contact increased during this period [231]. When examining AIDS incidence specifically between 1982 and 1991, a review found only 3% of cases among women, and 91% of cases in men linked to homosexual intercourse [232].

Society and politics

The emergence and spread of AIDS in Australia coincided with political times favouring liberal and participatory policies. Since the 1960s, traditional political structures in Australia were gradually being displaced by groups aiming to improve the status of women, indigenous peoples, ethnic minorities, disabled people, and the LGBT+ community. The centre-left Australian Labour Party (ALP) held the majority government throughout most of the 1980s. The ALP was supportive of preventative and community health programmes and was willing to enable political centralisation of the HIV/AIDS response [225].

The federal government in Australia was the structure that allocated responsibilities between the federal government in Canberra, six states, and two self-governing territories. While the federal government took on national responsibility, state and territory governments assumed

responsibility for provisioning funding and service delivery in response to the epidemic. Ministers across sectors joined the fight against HIV/AIDS, with those responsible for drug law enforcement, welfare, housing, insurance, human rights, immigration, research, prisons, and education collaborating in a united, multi-faceted response [225].

Two national advisory structures were established in November 1984 to front efforts against HIV/AIDS. The National Advisory Council on AIDS (NACAIDS) targeted prevention education, care, and treatment, while the AIDS Task Force allocated research budgets and increased clinical and epidemiological expertise [225, 233]. Both advisory structures provided input on policies, allowing for effective communication from the front-line through ministerial decision-making and implementation.

The following year, in November 1985, parliament instituted the Parliamentary Liaison Group on AIDS. All politicians in the Liaison Group were welcome to participate in briefings about HIV/AIDS. It is considered that by increasing awareness of the epidemic and potential policies, the group allowed for better informed debate and strategic input [225].

AIDS had been linked to the highly emotionally charged issues of attitudes towards LGBT+ people and homophobia everywhere. However, a key feature of Australia's response to the HIV/AIDS epidemic during the 1980s was their involvement of and joint decision-making with community-organised groups. "Grassroots" activism had already gained traction within LGBT+ communities during the 1970s and early 1980s [224], with previous focal points centred on



Figure 4.2 Condoman, a cartoon figure, holds a packet of condoms on a beach; advertising safe sex among indigenous Australians. Colour lithograph by the Department of Health, Housing and Community Services, Australia (poss. 1995), and the Aboriginal Health Workers of Australia (Queensland). Attribution-NonCommercial 4.0 International (CC BY-NC 4.0)

fighting oppression, discrimination, and the criminalisation of gay sex [224]. These prior efforts underpinned mobilisation against the spread of HIV and the establishment of AIDS Action Committees in state capitals. In 1983, the New South Wales (NSW) AIDS Action Committee in Sydney and the Victorian AIDS Action Committee in Melbourne emerged.

Through the formation of subcommittees inspired by gay activist organisations in New York City and San Francisco, the Action Committees became state and territory-level AIDS Councils in 1985 [224, 220, 233]. These and other community-organised groups played an early and important role in, among other initiatives: gathering information on AIDS, educating their peers, organising fundraising and educational campaigns, and lobbying politicians [225]. For example, the Councils disseminated preventative education through innovative workshops and posters on safe sex (Figure 4.2) [233]. Following this, other at-risk groups, including IDUs, sex workers, and haemophiliacs also mobilised during this period.

Through personal experience and the development of specialised knowledge about HIV/AIDS, community-organised groups provided insights into government-led initiatives and policy development. In addition to their role in the political process, these groups, which achieved partial or full governmental funding, also played a role in advocacy, gathering and disseminating information, and providing financial and emotional support services for individuals living with or at risk of infection with HIV [224, 225]. Amid instances of discrimination towards the gay community and individuals living with HIV, activist groups took a firm stance in fighting stigma and legislation that had the capacity to be harmful [224, 233]. For example, in response to an amendment led by NSW Premier Neville Wran which required notification of HIV/AIDS diagnoses to health authorities, the gay community mobilised hundreds of individuals who reported for HIV testing under the pseudonym “Neville Wran” [224, 233].

Starting in 1984, the Australian Minister of Health, with regular input from community groups, clinicians, and researchers, led the government in developing a strategic, cross-cutting response. The government implemented a series of educational, social, political, public health, educational, and cultural initiatives to increase awareness, reduce stigma, and prevent further increases in HIV transmission.

Economy

The development of the national economy in Australia in the 1980s followed the political and governmental progress. At the start of the decade, the Australian economy was characterised by high inflation, industrial disputes and high unemployment. The federal government recognised that the economy needed restructuring and stability if its policies were to be implemented successfully [234].

The decade that followed saw the globalisation of the Australian economy, along with privatisations, attempts to minimise inflation, implementation of social services and deals with trade unions [235]. Throughout that decade and the next, following a broad reform agenda – which included the important Australia’s National Competition Policy, Australia’s economy gradually transformed into an open, dynamic and flexible economy focused on high productivity [236].

The devolution of responsibility for funding the delivery of public health services partly to states and territories was an important part of a successful response to AIDS in terms of resource allocation. This led to Australia having perhaps surprisingly good health outcomes when considering that the public health spending as a proportion of the GDP was average for a high income country [237].

Healthcare and public health

Efforts to respond to the spread of AIDS quickly focused on finding treatments that would be effective. The first drug approved to treat HIV was Azidothymidine (AZT). Initially developed for cancer in the 1960s, AZT was tested as a treatment for HIV during the 1980s and approved for use in March 1987 [238]. Despite side effects including gastrointestinal distress, headaches, and fever, and in more severe cases liver and muscle damage, AZT was in high demand at the time as the only available option. In subsequent years, other medications were approved for use, with physicians assessing which drug worked best for the individual.

Later on, treatment switched to the combination of three or more antiretroviral drugs (ART), the Highly Active Anti-Retroviral Therapy (HAART). While ARTs have been effective in suppressing viral load, HIV can progress to AIDS if left untreated. HIV attacks CD4, or T-cells, which are vital in coordinating the body’s immune response. If a person’s CD4 count drops below 200 cells/mm³ of blood, they are considered to have advanced to AIDS. By impairing the immune

system, AIDS leaves the body vulnerable to opportunistic infections and certain cancers. A study conducted in 1989 identified a median development time of 11 years for HIV to progress to AIDS [239]. Other early research indicated that many individuals did not present to care for five or more years after initial infection, at which point low CD4 counts indicated chronic infection [240, 241]. Throughout the 1980s and 1990s, without treatment, the life expectancy for someone with AIDS was around three years from infection and this could drop to under one year if the individual developed certain infections. Since no treatment was available for HIV during the early 1980s, most HIV infections advanced to AIDS [242].

The Australian health system provided a systematic response to AIDS, starting by introducing national health insurance through Medicare in 1984. Alongside government funded HIV test kits, Medicare entitled citizens to anonymous, free HIV testing, as well as free access to HIV care and subsidised access to AZT [225]. These measures certainly helped combat the fear of stigma of the disease. The NSW Department of Health established an AIDS hotline at the end of 1984 to support affected communities, while the Albion Street Clinic and other services implemented testing and counselling programmes to support individuals to cope with their diagnosis [224].

Subsequently, in April 1985, the “Drug Summit” brought together the Prime Minister and provincial governments to discuss opportunities for harm reduction [225]. During this meeting, stakeholders discussed that reducing harm associated with injected drug use, particularly preventing new HIV infections, was more important than reducing drug use by itself. Despite parliamentary debate and public concern, Sydney piloted its first needle and syringe exchange programme (NEP) one and a half years later. With origins tracing back to the 1970s and the first government-approved NEPs running in the Netherlands in 1984 [243, 244], these programmes provided individuals with safe, sterile injection equipment while also increasing access to HIV preventative education, testing, treatment, and counselling. Under community pressure, the NSW government allowed NEPs to operate legally starting in 1987, following which, other Australian states and territories started similar initiatives. The NSW government also amended prior legislation which regulated the sale of needles and syringes in retail pharmacies [245].

NEPs were particularly effective in containing infections among IDUs and MSM and preventing further community transmission. Despite initial scepticism, pharmacists’ attitudes vastly improved within four months of the distribution program, with a 20% increase in the number of Pharmacy Guild members involved in efforts during 1987 [245]. Furthermore, 422,000 clean needles and syringes were sold at retail pharmacies in NSW from January to November 1987

[245]. NEPs and pharmacy sales were important in further curbing the spread and incidence of HIV infections. Evaluations of data from 1991 calculated that NEPs in Australia prevented between 300 and as many as 10,000 new HIV infections. It is estimated that prevention of infections attributable to NEPs yielded cost savings in treatment that outweighed the operational costs of the programmes themselves, particularly when factoring in prevention of other blood-borne infections such as Hepatitis B and C [225].

Australia also increased investment in methadone maintenance treatment (MMT) for opioid addiction during this period. MMT units were sometimes built adjacent to NEPs [246], furthering efforts to minimise risks of HIV infection associated with injection drug use [225, 247]. A contemporary study looking at the effectiveness of MMT programs on HIV-risk behaviours among IDUs in Australia found that individuals currently on MMT showed significantly lower injection risk behaviours than individuals who had discontinued or never been on MMT [248]. In response to HIV transmission through blood transfusion and blood products, Australia also began screening all blood donors for HIV antibodies in 1985 [249].

To further support an effective public health response, the Australian government invested in HIV/AIDS research with guidance from the AIDS Task Force. The National Centre in HIV Epidemiology and Clinical Research (NCEHCR), the National Centre in HIV Social Research (NCHSR), and the National Centre for HIV Virology Research (NCHVR) were all funded to direct research on HIV/AIDS. Partnering institutions, including the Burnet Institute and Albion Street Centre, also supported infrastructure for HIV/AIDS research, and in collaboration with New Zealand, Australia helped establish the Australasian Society of HIV Medicine (ASHM) which supported knowledge sharing with the health workforce [225]. Investment by affected communities sparked high enrolment and participation in clinical and epidemiological research studies, for example, the Sydney AIDS Project [224, 250]. These studies helped increase the knowledge base, inform a responsive public health response, and ensure effective treatment delivery.

Culture

In the early years of the AIDS epidemic in Australia, sensationalist reporting of rumours and speculation were common [226, 251], and reports were often quick to blame the victim [158, 252, 253]. Even at the governmental level, some perceived AIDS as a product of deviant

lifestyles, with one state Minister commenting to Federal Health Minister, Neal Blewett, on record: *“Look, mate, there are no votes in buggers, druggies and prozzies!”* [226]. Negative media attention towards individuals in high-risk groups provoked hostility and discrimination at a time when little was known about the disease [158] – this is, of course, a common theme in many epidemics impacting on early emotional public and political responses.

In 1981, Australian gay press published reports of a “rare viral cancer” that had been spreading in America [224]. A review of press articles published more broadly in Australia from 1981 to 1985 delineated a transition in reporting across three phases [254]. Reports from the first phase, from 1981 to 1984, focused on gay men, with the first reports referring to AIDS as GRID. By this point, only MSM seemed to be affected by AIDS, and articles commonly referred to AIDS as a “gay disease” or “gay plague” [255].

In 1984, three babies died in Queensland after receiving HIV-infected blood transfusions. The spread of HIV infection beyond MSM and the death of these babies sparked renewed homophobia and a transition to the second phase of reporting. Vilifying the gay community, some reports argued that the deaths were deliberate attacks by gay men on innocent lives.

The third phase of reporting in the first half of the 1980s were framed around reports of a young Australian girl, Eve van Grafhorst, infected with HIV through blood transfusion. After news spread of her infection, the girl and her family faced immense discrimination, including expulsion from kindergarten and eviction, which ultimately led her family to flee to New Zealand. Reports documenting this case continued to emphasise gay men as the main group affected by HIV, with some reports describing concerns with blood products and scattered headlines suggesting heterosexuals could be at risk [254, 256].

As the epidemic continued to spread among MSM and IDUs in the mid-1980s and sensationalist reporting stoked misperceptions and fears, a senior advisor to the Health Minister, William Bowtell, noted that there would be value in a strategic mass media response. The Australian government and HIV/AIDS minister took over media coverage of the epidemic in 1983, establishing media units to provide accessible, frank, and responsive information [225]. Aiming to deliver a prevention message for the wider public, a steering committee of NACAIDS coordinated a AUD 3.63 million campaign [233].

William Bowtell, a member of the committee, scouted an advertising agency that would use television media to play at fears and build awareness and concern. Simon Reynolds, from Grey

Advertising in Sydney, developed the “Grim Reaper” storyboard. Ida Buttrose, chairperson of NACAIDS, was quoted in the *Melbourne Age* as stating that the campaign was conceived “to stop people in their tracks and make them think seriously about AIDS” [158]. Despite concerns and pushback from Health Minister Neal Blewett days before airing, NACAIDS proceeded to air the commercial starting April 5, 1987 [226, 233].



Figure 4.3. Screen grab from the Grim Reaper television advertisement.

At just over one minute in length, the television-based public service announcement employed imagery and sound reminiscent of a horror film (Figure 4.3). The advertisement begins with a pinsetter lowering seemingly innocent men, women, and children. The face of death flashes as the grim reaper throws a bowling ball down a lane of smoke, knocking everyone dead. The narrator describes:

“At first, only gays and IV drug users were being killed by AIDS. But now we know, every one of us could be devastated by it. The fact is, over 50,000 men, women, and children now carry the AIDS virus. That in three years, nearly 2,000 of us will be dead. That if not stopped, it could kill more Australians than World War II.”

As the sweep bar discards the dead bodies, the narrator continues,

“But AIDS can be stopped, and you can help stop it. If you have sex, have just one safe partner, or always use condoms. Always.”

With that, the grim reaper fades behind a storm of ominous clouds, and “*AIDS. Prevention is the only cure we’ve got.*” displays on screen, followed by a telephone number for the AIDS support hotline [257]. The Grim Reaper campaign was supplemented by print materials which provided additional information on the disease, including prevention measures and routes of transmission. State and territory-level governments, in partnership with HIV/AIDS community groups distributed prevention materials (condoms, needles, syringes) in high-risk settings such as bars, clubs, brothels, and beaches. The same year, Blewett revised health education curricula in secondary schools to include discussions of homosexuality and safe sex [233].

The Grim Reaper campaign sparked immediate debate. Some complained that the commercial did not provide enough information about AIDS, some thought it over-emphasised the risk among heterosexuals, and others believed that the leaflets would facilitate infections by increasing sexual experimentation among young people. The debate spread to newspapers and academic journals. Editorials and columns argued that the campaign was driven by the “gay lobby” as a way to shift attention and blame away from the gay community as the primary risk group [233]. Letters to newspapers complained that the commercial was unnecessarily scaremongering or frightening to children [226].

Furthermore, the campaign inadvertently demonised members of the gay community. Immunologist Dr. Ron Penny noted, “*The downside was that the Grim Reaper became identified with gay men rather than as the Reaper. That was what we had unintentionally produced - [the belief] by some that the Reaper was people with HIV infection, rather than the Reaper harvesting the dead*” [258]. Others similarly criticized the fear tactics employed in the campaign as stigmatising gay men and harmful to those living with HIV [259, 260].

Despite its downsides, the Grim Reaper campaign seems to have been well-remembered, increased awareness of HIV/AIDS, and had positive impacts on risk behaviours [261]. News bulletins and stories universally took up the grim reaper imagery, and while the commercial only aired for three weeks in April, the imagery was broadcast across media sources for years. A survey conducted midway through airing the commercial found that 97% of respondents had seen the campaign [233], and a daily paper from Sydney saw a 400% increase in mentions of HIV/AIDS between 1986 and 1987, in direct response to the campaign [225, 158].

As the public learned that anyone could be affected by HIV/AIDS, the “newsworthiness” of the epidemic increased rapidly [158]. Some headlines broadcast, “*AIDS: Even Your Best Mate Could Have It!*”, while others read, “*AIDS is Not Just a Gay Plague*” [158]. From 1986 on, and further

fuelled by the Grim Reaper campaign, press increasingly discussed the importance of condom use [158]. Evidence suggests that the campaign led to widespread increases in condom use and safe sex practices [233]. While some news reports disseminated after the campaign shifted blame to people with multiple sex partners [158], by 1990, most reporting had shifted away from reactionary headlines to objective reporting of education campaigns, exposure risk among certain professions, political and law implications, and treatment [262].

Emotions around the AIDS pandemic in the literature

Faced with a new condition that for years was incurable, public health communications on AIDS for decades were focused on prevention and vulnerable groups. The sexually transmitted nature of the virus lent itself well for awkward or mis-targeted government communications around the world, and leaning on the social history of addressing diseases like this through public health messaging, such as syphilis [263], meant that – not unexpectedly at all – a range of emotional responses were born.

Indeed, AIDS was the second most studied infectious disease in my systematic review with 21 studies assessing whether public emotional responses led to uptake of public health interventions. Sixteen of these studies have been published between 1988 and 1995, prior to the wider introduction of potent combination treatment in 1996 [264]. A total of 26 correlations between an emotion and an outcome were assessed across the included studies, 24 of which referred to unpleasant emotions, and two to pleasant emotions. In half of all the studies the emotion of fear was assessed. The most common outcomes (personal actions) studied were getting tested or using personal prophylactic measures (in the case of AIDS, predominantly related to safe sexual activities).

There was evidence that unpleasant emotions had a negative effect (that is, lack of action) on the uptake of public health interventions in the settings studied with 17 out of 24 correlations showing a lack of action on uptake of interventions ($p=0.063$). The evidence was stronger on the correlation between extreme unpleasant emotions (fear, panic and shame were used) and uptake of interventions, with 15 out of 19 correlations showing lack of action ($p=0.019$). All the studies included in my review in the first period of between 1988 and 1998 were of medium and high quality, bar one [151].

Pleasant emotions were used in two studies, both in the early 1990s, leading to action in both instances. Interestingly, in one of these studies from the US in 1991, in depth qualitative research was conducted with 21 women who were deemed as high risk for contracting HIV as intravenous drug users or heterosexual partners of intravenous users (IVUs). The high quality study, which used the Health Belief Model, found that hope – and not belief that recommended health behaviours would be effective – was the key driver for the women to practice safe sex [157].

Discussion – The emotional determinants of the response to the AIDS epidemic

Following the first reports of HIV/AIDS in Australia, discrimination towards people living with HIV was frequently reported, including blatant hate crimes [224]. Amidst an early lack of communication about the disease, fear and panic incited public demands to quarantine entire communities [225]. Before legislation mandated HIV antibody testing of all donated blood, a survey of 2,000 Australians found that almost half feared they might contract AIDS in a hospital or if they received a blood transfusion [233]. Despite early stigma, victim-blaming, and fear of exposure, the multi-tiered response to the epidemic provided citizens with clear, digestible information that increased awareness and acceptance of HIV/AIDS. Furthermore, the increasing acceptability of disclosure within gay communities by the end of the 1980s helped some men cope with the difficult emotions of their diagnosis while also giving them a sense that they were not alone [224, 265].

While early reporting of the HIV/AIDS epidemic around the world often vilified MSM [158, 254, 256, 266, 267], Australia's Grim Reaper campaign illustrated that all individuals, including those practicing heterosexual intercourse, could be at risk. Interestingly, in my systematic review, the Grim Reaper campaign, based on a high quality national campaign evaluation [148], is one of only four studies showing that evoking the emotion of fear could lead to uptake of public health interventions. In most studies, the opposite was the case. Counterintuitively (to the clear indications from the literature that fear-based campaigns do not work), what seemed to have worked in the other three studies was the targeting of specific population groups with nuanced or advocacy-based messaging [156, 161, 168].

Hence, we can reasonably assume that in the case of Australia, a key factor to the success of the education and prevention programme was that the fear-evoking Grim Reaper advertisement

was not at the core of the programme, rather playing a small role, sitting alongside a range of empowering community-led initiatives through which Australia's government and partnering organisations disseminated transparent information about and resources for HIV/AIDS. These provided the public and key risk groups with knowledge as it was produced.

Through the strategic response to the HIV/AIDS epidemic, Australia was largely able to avoid some of the misperceptions around transmission that were common through the late 1980s and 1990s in other regions of the world [154, 149, 164, 163]. Evidence from Australia consistently indicated widespread knowledge around HIV/AIDS and routes of transmission. A Sydney-based telephone survey in 1988 and 1989, for example, found high knowledge scores on HIV transmission and prevention among 16-50 year-old respondents, with many citing the Grim Reaper campaign and associated news as their knowledge source [261].

Nevertheless, despite these knowledge gains, some confusion persisted around the actual risk of infection. While a survey of 655 Australian general practitioners found that most valued the importance of HIV screening and education in their work, some overestimated the risk associated with certain low-risk activities while underestimating the risk among heterosexual individuals. Furthermore, 16% of the survey sample reported it would be acceptable to refuse to treat someone living with HIV [268]. Evident stigma toward HIV carriers and a counterproductive fear of infection seen among these practitioners reflect research from Sweden [152] and other places, and highlight remaining gaps in risk perceptions at the time, even after wide dissemination of educational materials. Fear and shame-based messaging in certain settings throughout the two decades following the emergence of AIDS contributed to these responses.

Increasing knowledge around HIV/AIDS and concern around infection in Australia prompted behavioural change among some cohorts. For example, a survey conducted between 1986 and 1987 with gay and bisexual men found increases in safe sex, particularly among non-monogamous men. Furthermore, some men reported increased selectivity of partners and reduced frequency of intercourse [269]. However, a study conducted with homeless and non-homeless youth found similar attitudes between the groups, but significantly lower knowledge and higher risk behaviours among the homeless youth [270]. Data from a private STD clinic in Sydney found that the campaign stimulated HIV antibody testing among individuals in lower-risk groups [230]. The Albion Street Centre also saw a notable increase in HIV testing among

heterosexual individuals and IDUs [148]. In the telephone-based survey in Sydney in 1988 and 1989, 80% of respondents had considered HIV testing for themselves [261].

Despite positive improvements in knowledge scores, sexual risk behaviours, and testing uptake, one study documented pervasive anxiety about AIDS and potential HIV infection [261]. A survey of Australian children and adolescents also found high levels of fear around AIDS, with the highest rates seen among females [271]. The Grim Reaper campaign itself was not equally successful among gay men [148]. All the above points to the need for sophisticated and multi-layered messaging speaking to the expected emotional responses in different population groups.

A history of emotional responses to AIDS in any context would be incomplete without the assessment of the emotional burden of the diagnosis. Those who tested positive for HIV/AIDS, as well as individuals whose partners or loved ones tested positive during the 1980s, faced a heavy emotional burden [224]. The HIV diagnosis, particularly at a time when there were little to no treatment options, carried trauma, fear, and responsibility [272]. Individuals feared disclosure and the thought of infecting another person, while many others experienced anxiety about their health and showing physical signs of the disease [224]. Before AZT was approved for treatment, HIV was seen as a death sentence. Coupled with early legislation mandating the release of HIV test results and stigma toward the LGBT+ community and people living with HIV, individuals feared disclosure. Thus, some men described distress and fear of ostracism when they began showing physical signs of Wasting Syndrome and Kaposi's sarcoma, both common indicators of an AIDS diagnosis [224].

An oral history of survivors of the HIV/AIDS epidemic in Sydney describes the painful reality of MSM during the 1980s. Individuals in the gay community witnessed friend after friend die of AIDS, leaving many helpless and grieving. During interviews, several respondents described moving out of Sydney, previously the epicentre of the LGBT+ community, to escape the trauma of loss [224]. For infectious diseases that take a chronic course and whose treatment and care shift over time, emotional responses evolve as well. This calls for a revision of public health messaging to effectively use these emotions among the public. In my systematic review, however, most studies conducted following the introduction of potent combination treatment in 1996 showed a repetition of the same mistakes of previous campaigns. Indicatively, two studies from the US, targeting at risk populations (one trans people and the other heterosexual black men), evoked the extreme emotions of shame, fear and hopelessness to motivate action,

all with a complete lack of correlation [165, 204]. The main scope of my thesis, though, is to focus on emotional determinants impacting on the response to epidemics as they emerge as health crises.

By 2003, a total of 20,580 individuals had cumulatively been diagnosed with HIV in Australia. The drop in incident HIV cases following a peak in 1984 and the subsequent drop in AIDS diagnoses can be largely attributed to the coordinated response by the Australian government and community-organised groups, as well as the approved use of AZT and subsequently, other ART drugs for treatment [225].

By including multiple sectors in the response, and acting at social, political, public health, educational, and cultural levels, Australia provided a clear, honest and transparent picture of the risks of HIV/AIDS and co-ordinated resources for affected individuals, accurately and effectively capturing and using the emotions of the public at the time. Although some misperceptions about and negative attitudes toward those living with HIV/AIDS persisted, the mid-to-late 1980s saw a clear shift away from high risk behaviours, indicated by increased HIV testing among lower risk groups, increased use of sterile needles and syringes among IDUs, and increased safe sex practices. These behavioural changes, indicative of increased awareness and acceptance of the realities of HIV/AIDS, are reflected in the annual reductions of HIV incident infections after 1984. Furthermore, programming and initiatives to support those living with HIV supported an environment where disclosure of personal experiences with HIV/AIDS became more acceptable, with a proliferation of stories and insights recounted during the late 1980s and 1990s. Considering the immense emotional distress tied to the epidemic, particularly among affected communities, this climate of disclosure supported individuals in navigating grief and complicated trauma.

In the years following the establishment of Medicare and NEPs, as well as the dissemination of the Grim Reaper campaign and other educational strategies, Australia continued to consult with affected community groups to map out strategies and action plans. In 1989, the government developed a comprehensive National HIV/AIDS Strategy which incorporated health promotion concepts from the 1986 Ottawa Charter [225]. Australia has now prepared the eighth national strategy (2018-2022). In addition to their national response, Australia continues to invest resources in global efforts against HIV/AIDS.

With one of the lowest rates of HIV/AIDS infection in the world, Australia's response to the AIDS epidemic during the 1980s should serve as a landmark example of a timely, collaborative, and

effective public health response. In doing so, it has helped provide an example of how the wider context in which an epidemic response is happening can be conducive to shaping public emotional responses that favour the uptake of interventions.

SARS in Hong Kong, 2003

Context

Severe Acute Respiratory Syndrome (SARS) first emerged in Guangdong, China in November 2002. Following superspreading events in Hong Kong in February and March 2003, SARS developed into a mass outbreak that spread across borders and permeated communities. As with other outbreaks of the late 20th century [273], non-transparent communication, misinformation, and a delayed international response put individuals at risk of illness and death while also fuelling mass panic [274]. The epidemic had vast physical, psychological, social, and economic impacts [275, 276].

Hong Kong became the major epicentre for the international spread of the virus when a doctor treating patients in Guangdong travelled to Hong Kong in early February 2003 [277]. The index case in Hong Kong, Dr Liu Jianlun was identified as a “super spreader” of SARS after he transmitted the virus to several people at Metropole Hotel. These individuals proceeded to spread the disease to Vietnam, Singapore, Canada, and back to China. Additional superspreading events occurred shortly thereafter in healthcare settings across these countries [278], and transmission subsequently continued among the wider community [279]. When one individual, who had been in contact with Dr Jianlun, was admitted to the Prince of Wales Hospital in Hong Kong, 138 more staff, patients, and visitors were infected during a 14-day period [279]. One of these patients was discharged quickly, leading to the infection of 329 residents at the Amoy Gardens apartment complex in Hong Kong [280].

Despite cases of atypical pneumonia identified in China since November 2002, the Chinese government failed to notify the WHO of incidents until a report in mid-February 2003. The report described more than 100 cases of an atypical pneumonia outbreak. The Chinese Ministry of Health reported an outbreak of acute respiratory syndrome, with 300 cases and five deaths, to the WHO on the same day [281]. Dr Carlo Urbani, a WHO epidemiologist, was treating a patient in Vietnam who had stayed on the same hotel floor as Dr Jianlun in Hong Kong, when he stipulated that the patient was likely suffering from a novel, contagious virus [279]. He promptly alerted the WHO of the “unknown contagious disease”. Although Dr Urbani contracted SARS and passed away while in intensive care in Thailand, his notification triggered a concentrated response to the epidemic. The WHO issued a global alert on March 12 [281, 282], and subsequently identified the virus as SARS in a second alert three days later [282].

In the period following these alerts, the WHO provided recommendations to healthcare workers on prevention and control measures and information on transmission and epidemiology. Airports began screening passengers and eventually, the WHO issued travel advisories to areas where not all cases had been traced. In early July 2003, the WHO declared the SARS outbreak contained, after the last probable cases had been isolated [281]. By that point, thousands of people had been infected across five continents, and hundreds had died. The epidemiology of the outbreak was shaped by the culture, society, and politics in the region and had considerable economic and psychological repercussions in Hong Kong.

Epidemiology

Three weeks after the outbreak hit Hong Kong, the disease was recognised as a novel coronavirus, identified as SARS-CoV [283, 284, 285, 286, 287, 288]. The emergence of SARS marked the first known coronavirus to cause potentially fatal infections in humans [289].

By July 2003, SARS had reached 29 countries across five continents [290]. Of the estimated 8,096 individuals infected globally, 774 had died. Over a fifth of the total infections and almost a third of these deaths occurred in Hong Kong, where the case fatality rate was 17% [290]. Mainland China, Taiwan, Canada, and Singapore each had more than 200 cases. The virus was more common among females, with the median age of individuals who contracted SARS below the age of 45 [279, 291]. Of the cases in Hong Kong, 22% were among hospital workers [291]. Common symptoms included fever, headache, fatigue, muscle aches, dry cough, and other respiratory symptoms as well as some gastrointestinal problems [292, 293]. Patients typically developed pneumonia, and in some cases, required ventilation [293].

Most of the early cases of SARS in Guangdong, China occurred among individuals in frequent contact with animals, including those involved in killing, handling, and selling wildlife in markets, and those involved in preparing and serving food from wild animals. Furthermore, most of these incident cases lived in walking distance to exotic animal markets [294]. Wild animal traders in Shenzhen, Guangdong, China were significantly more likely than vegetable traders to test positive for SARS antibodies in one study [295], and another study found that almost three-quarters of masked palm civet traders tested positive for the same antibodies [296].

To establish how the first humans contacted the virus, researchers conducted Polymerase Chain Reaction (PCR) techniques on nasal and faecal swabs from various domestic and wild animal

species from an exotic animal market in Shenzhen [295]. Six masked palm civets, a raccoon dog, and a Chinese ferret badger tested positive for SARS isolates or neutralising SARS antibodies, providing evidence for animal-to-animal transmission [295]. Further studies confirmed a striking susceptibility among masked palm civets to SARS [297, 298]; civets were thereby recognised as an amplifying host for SARS due to their vast distribution in markets and the food industry.

Later research identified wild Chinese horseshoe bats as the reservoir host [299, 300]. As live bats are also commonly traded in exotic animal markets, it is likely that bats may have infected civets during trading, potentially through faecal shedding [296]. Civets, in turn, likely infected some of the first index cases of SARS.

Although it took time to understand definitively how the virus was spreading, researchers and practitioners determined the primary routes of transmission: droplets, aerosols, and fomites [288]. The mass outbreak in the Amoy Gardens apartment was traced to contaminated waste drainage pipes and aerosolisation of faecal matter [280, 292]; however, some research suggested the role of human-to-animal and subsequent animal-to-human transmission in the apartment outbreak, through either domestic cats [301] or infected rats [302].

Although the average incubation period for the virus was 6.4 days [279], some individuals did not show SARS symptoms until 10 days post-infection [303]. Due to the long incubation period, several people travelled by air before showing symptoms, further inciting cross-border transmission [303]. Poor surveillance, particularly early on, spurred widespread transmission through superspreading events.

Society and politics

Hong Kong has a special administrative status since China and Great Britain signed the Sino-British Joint Declaration for the return of Hong Kong to China in 1984 covering a period of 50 years since 1997. This agreement was to give Hong Kong a high degree of autonomy and a policy of democratisation. However, by the mid-2000s, China had a diminished interest of opening up to the outside world and was increasingly using subversive politics in Hong Kong, including hand-picking business elites to rule the region [304, 305]. It was in this tense political context that SARS emerged.

In 1997, the WHO established the Global Outbreak Alert and Response Network (GOARN) [273]. The GOARN collected information and resources to mount concentrated responses to global

outbreaks and maximise health security. Although the GOARN had started picking up on media reports of an influenza outbreak in China in November 2002, and continued collecting clinical and epidemiological data in China, Hong Kong, and Vietnam, the WHO did not issue a global alert until mid-March 2003 [273]. By that point, SARS had touched the lives of individuals across east Asia and beyond (Figure 4.4).



Figure 4.4. People stand under a freestanding green umbrella which protects them from the rain; representing the protection conferred by the Infectious Diseases Prevention and Cure Law (Revised) in China in 2004. Colour lithograph, 2004. Credit: Wellcome Collection. In copyright.

After the Prince of Wales Hospital in Hong Kong admitted its first SARS patient, the Dean of the Faculty of Medicine of the Chinese University of Hong Kong warned of a forthcoming community outbreak [306]. However, fearing inciting panic, government officials ignored medical doctors' requests to close the Prince of Wales Hospital on March 10 [306]. A week later, the Secretary for Health, Welfare and Food further negated claims of the upcoming outbreak, arguing that the spread was contained among medical staff and patients' relatives. After the Chief Executive of the Hospital Authority was infected, however, the highly contagious nature of SARS quickly became evident. At the end of March, after hundreds of individuals had already been infected, the Hong Kong government finally began enacting strict quarantine measures and school

closures. By this point, local businesses already felt dramatic economic shocks, parents had removed their children from school, and public fear was rampant.

As the local government initially understated the seriousness of the outbreak and delayed action to contain transmission, public critique of the response grew. In April 2003, a survey found that 65% of respondents found Hong Kong Chief Executive Tung Chee-hwa incompetent in his handling of the epidemic [306, 307]. Some citizens, concerned by the government's poor and fragmented communication about SARS, set up a grassroots website, "sosick.org" to provide transparent information and personal insights on the outbreak [308, 309]. The government was further criticised for relying on travellers' self-reported symptoms. Limited testing at points of entry and travel allowed spread beyond Hong Kong's borders. In July 2003, 500,000 people demonstrated in Hong Kong, demanding Chief Executive Tung to step down, partially due to criticism of his handling of the epidemic. A year later, Hong Kong's Secretary for Health, Welfare and Food stepped down from office, assuming responsibility for the outbreak. Criticism of the SARS response in mainland China was also widespread, leading to the removal of both the National Health Minister and the mayor of Beijing [310].

Regarded as an "administrative state" rather than an independent political body, Hong Kong utilised civil servants in enacting procedures, problem solving, decision making, and managing resources. Despite press reports in February 2003 describing hundreds of SARS cases in Guangdong since November, health care authorities and civil servants were not equipped with contingency plans or prepared to respond to a crisis situation [306, 311, 312]; rather, they waited until the SARS outbreak was undeniable to take decisive action [306]. The disjointed administrative institutions, and lack of a centralised management structure made decision-making and resource allocation difficult. Furthermore, because the Hong Kong government was constrained by China, the government faced concerns over enacting immigration control at the Shenzhen border and describing Guangdong as the source of the epidemic [306], particularly since the Chinese government had veiled the severity of the outbreak early on.

Although the Hong Kong government eventually took measures to control further spread of SARS, institutional unpreparedness, indecisive decision-making, poor political leadership and community mobilisation, and lack of crisis mentality fuelled the slow response [306]. Failures of the bureaucratic response amplified an unnecessarily high sickness and death toll in Hong Kong and beyond. The need for national and international governance bodies to be equipped with

cohesive emergency response teams and surveillance mechanisms became readily apparent in these circumstances.

Economy

The SARS outbreak impacted the global economy, with vast repercussions for economies in Asia. Following the Asian financial crisis in 1997, Hong Kong experienced a long economic slump, with rising unemployment and deflation. Beliefs that an economic turnaround depended on integration with mainland China and fears that transparent communication about SARS would further damage the economy, the Hong Kong government withheld information, thus preventing proactive containment measures and leading to economic losses [306].

Quarantine measures across Asia, Canada, and the United States caused financial hardship and a reduction in consumerism [313, 314]. Furthermore, in the face of travel advice and public fears around transmission, the demand for tourism and air travel plummeted, dramatically impacting consumption of these service industries [315].

Particularly in Hong Kong, where the service industry dominates the economy, quarantine measures, border closings, school suspensions, and public anxiety hampered business at public venues including restaurants, hotels, marketplaces, and airports [306, 172]. In the first two weeks of April, 25 restaurants were closed, 1,600 staff became unemployed, and 16,000 members of the Hong Kong Federation of Restaurants and Catering Services were forced to go on unpaid leave or take pay cuts. Tour companies' and retailers' revenue plummeted, while hotel occupancy dropped 65% and airline passenger rates dropped 60% [316]. On April 2, the WHO issued an official travel warning to Hong Kong, further shocking the local economy [306]. Avoidance triggered by fear of infection also led people to avoid service-related activities. During the outbreak, exports and trade from Hong Kong decreased by \$23.1 billion [317].

In addition to the impact on consumer demand, the uncertainty around SARS and the lack of transparency early on impacted confidence in the economies of the countries most impacted. With weakened confidence in China, Hong Kong, and other affected nations, foreign investors pulled out of investments [282]. Economists estimated a loss of \$30 billion across Asian states [318] and \$40 billion globally in 2003 alone [282]. Alongside global economic losses, China and Hong Kong experienced shocks to their GDP based on simulations using the G-Cubed model. This model considered initial shocks to the region and global exposure, and calculated that China's

GDP dropped 1.05% [282, 26, 319], while Hong Kong's GDP dropped an estimated 2.63% during 2003 [282]. However, despite impacts on the economy during the peak of the epidemic, service industries in Hong Kong rebounded in the second quarter of 2003, following containment of the virus. Industries saw increases in consumption as well as steady increases in other economic indicators.

Healthcare and public health

Several measures were taken to isolate cases and prevent onward transmission of SARS in Hong Kong. Despite such measures, institutional bodies faced criticism for certain public health actions as well as for the delayed response. The fragmented health system in Hong Kong, with different departments and authorities in charge of different sectors, made communication and control difficult [274]. In Singapore, Canada, and China, SARS patients were treated in isolated hospitals; however, in Hong Kong, SARS patients were distributed across major, public hospitals. This increased risks of community transmission also meant that some patients were placed into hospitals which were poorly equipped with staff and resources [306].

While the Department of Health tracked upwards of 26,000 individuals who had been in contact with potentially infected patients, due to understaffing and the rapid spread, they were unable to trace all sources. After the outbreak in the Amoy Gardens apartment complex, Block E residents were quarantined for 10 days, and anyone who had had close contact with someone infected with SARS had to be examined. The next day, residents were moved into quarantine camps [168]. Quarantined individuals' medical status and compliance were monitored by the Hong Kong Department of Health and the police force. From the end of March to May 2003, primary, secondary, and university classes were suspended in Hong Kong as the Education and Manpower Bureau (EMB) joined forces to control the spread of the disease [320]. The EMB further urged parents to keep their children home during this period, although many parents had already taken their kids out of school due to fears of infection. Simultaneously, Hong Kong residents were encouraged to wear face masks when out in public, a practice that more than 90% of residents adopted [321]. On March 15, the WHO advised people traveling from Asia to be cautious of flu- or pneumonia- like symptoms [282], and in early April, the WHO issued an official travel advisory against travel to Hong Kong [168]. This advisory was removed on May 24.

The public health response in Hong Kong involved international support from the WHO. The WHO's GOARN mobilised a team of 60 experts in Hong Kong and other affected areas; this team supported case management, surveillance, and epidemiological investigation [322]. The WHO provided additional guidance throughout the epidemic, including through situation updates and risk assessment and preparedness guidelines and recommendations.

As it took time for scientists to establish how SARS was spreading and communicate accurate information, the public developed views on transmission in a “bottom up” fashion. Population-based telephone surveys in Hong Kong found that most residents held a range of confirmed and controversial theories on transmission, often fuelled by reported emotional disturbance and anticipated panic [174]. However, despite discrepancies in knowledge early in the outbreak, surveys conducted in later months demonstrated high SARS knowledge scores among Hong Kong residents. This provides evidence for improvements in communication about SARS transmission and precautionary measures as the region moved from the early to later phases of the epidemic.

Despite the initial delayed and disorganised response to the outbreak, subsequent actions by Hong Kong health authorities and the WHO, including a commitment to enforcing surveillance practices, quarantine measures, and travel restrictions, led to the eventual containment of the virus. Hong Kong residents' adherence to recommended precautionary measures further prevented a potentially more fatal and long-lasting public health emergency.

Culture

Exotic animal markets are common in China, with live animals traded for their fur, meat, and medicinal properties. Traditional medicine, specifically, is pervasive in Chinese culture. Ancient healers and scholars described remedies derived from natural herbs and animal products [323]. In zotherapy, human ailments can be treated by medicine made from animal bodies, secretions, and materials (such as nests and cocoons) [324]. Bats are one species commonly used in traditional Chinese medicine [325]; the literature describes benefits of bats and bat by-products on longevity, anaemia, eyesight, night vision, cough, and other maladies [324]. In addition to trading for their fur and meat, civets are also used in traditional medicine. *Woohwangchungsimwon* (WCW), for example, is derived from civets and purported to treat hypertension, stroke, arteriosclerosis, and coma [326].

In exotic animal markets, traders often handle multiple live animals at once, piling cages with different animal species on top of one another. Embedded in a culture of wild animal trading for fur, meat, and traditional medicines, this practice breeds an environment where viruses can jump the species barrier more easily [296]. As evidence emerged for the epidemiological consequences of such markets during the SARS epidemic, authorities cracked down on farming and trading practices. Civet trading, specifically, was banned in May 2003 [296]. Thousands of animals were confiscated, and hotels, restaurants, and markets were searched, often at the expense of farmers and traders' livelihoods [327]. However, as the SARS epidemic decelerated, exotic animal markets were reopened for trading, with the ban on civet trading removed in August 2003 [296].

In addition to the practice of live animal trading fuelling the emergence of SARS, a culture of rumouring and sensationalist media also surfaced throughout the epidemic. Facing significant uncertainty, anxiety, and perceived threat [328, 329, 330], as well as in the absence of state-sanctioned information about SARS during the early stages of the epidemic, individuals and newspapers spread rumours about the disease. These circulated rapidly across China [331, 332, 333]. Rumours were most prevalent in Guangdong and Beijing, the two hardest hit regions of China, and primarily spread through word-of-mouth [331].

While less pervasive than in these regions of China, some rumours also spread through Hong Kong. One study identified rumours of four types: legendary, aetiological, proto-memorates, and bogies [331]. Legendary rumours derived from traditional folktales and urban legends and embodied a range of Chinese ritualistic practices. Aetiological rumours were born from speculation about the causes, prevention, and treatment of SARS. For example, in Guangdong, individuals believed that boiling white vinegar could prevent and control the spread of the disease [334]. Following that, communities quickly depleted stores of their white vinegar stocks [331]. However, rooted in Chinese traditional medicinal practices, this rumour turned deadly, as one newspaper reported the death of two individuals, in two separate incidents, who died by carbon monoxide poisoning after burning charcoal to boil the white vinegar [335]. Proto-memorate rumours were most common and based on "eyewitness" accounts, including either from personal experience or hospital stories. Last, high levels of anxiety spurred bogus rumours, which capitalised on public fear. These rumours vowed insider information on systematic developments. For example, common rumours included unsubstantiated accounts of supply shortages and city blockades and closures [331]. While other rumours were less common in Hong Kong, some fake rumours emerged in the region, including that Chief Executive Tung Chee-

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hwa had resigned, that Hong Kong would be closed off from the world, and that the stock market had crashed [274].

Further provoking fear and anxiety, news media dramatising SARS were published within and beyond Hong Kong and China's borders during the peak of the epidemic [336]. For example, the BBC published one article, its headline reading: "*Concern is mounting over the continuing spread of the deadly SARS virus. Some experts say it could have a similar impact to the 1918 flu epidemic that killed 50 million—or the current world HIV crisis*" [337]. Another headline in Beijing read, "*China has threatened to execute or jail for life anyone who deliberately spreads the killer SARS virus*" [338]. Such reports played to the public's fears, sensationalising the epidemic by describing it as a "killer" and comparing it to other public health emergencies without adequate evidence.

The public frenzy brought about by the media attention prompted a culture of stigma and discrimination. People perceived to be at the highest risk of contracting SARS faced high rates of stigma and discrimination [339], as did individuals who looked of Asian descent, regardless of their actual nationality or risk factors [336]. Individuals who most feared stigmatisation and marginalisation experienced increased fear and self-stigma and were reportedly more likely to deny early symptoms and delay care. To combat stigma, racism, and avoidance practices, the National Center for Infectious Diseases' (NCID) SARS Community Outreach Team performed situational analyses, met with Asian communities in the United States, and implemented community interventions and outreach activities to dispel myths, strengthen resilience, encourage help-seeking, and mitigate fears [336].

Emotions around the SARS epidemic in the literature

The SARS epidemic which occurred in a highly politicised context and saw rumours and media playing an important role in the spread of information, is an important case study in considering the role of emotions. SARS was the third most studied infectious disease in my systematic review with 10 studies (attempting 12 correlations between emotions and outcomes) assessing whether public emotional responses led to the uptake of public health interventions. Almost all of the studies were published in the years immediately following the epidemic.

There was evidence that moderate anxiety-related emotions had a positive effect on the uptake of public health interventions in the countries studies with all six correlations showing a

motivation for action on uptake of interventions ($p=0.031$). This clearly points to the role of “worrying” as a motivator for action. In the case of SARS, action was predominantly targeted to following government issued recommendations, such as compliance with quarantine, reduced travel and avoiding crowded places.

Out of three studies conducted in Hong Kong, on a total population of 7,559 people, a positive dose-response gradient between manageable anxiety levels and uptake of personal protective measures was noted [175], though male participants, the youngest and oldest people in the sample, and people with lower educational levels were less likely to engage in self-protective behaviours [175, 340]. On the other hand, feeling unnecessary panic was counterproductive, suggesting a lack of action on seeking care [174].

Two high quality cross-sectional studies from Canada assessed the association between feelings of empathy, hope and wishful thinking in relation to taking recommended health precautions [172, 180]. They found that empathetic responding and perception of the threat of SARS was significantly and independently associated with following public health measures, such as avoiding crowded places [180]. The evidence on hope and wishful thinking, on the other hand, were not conclusive with evidence showing that hope was associated with uptake of interventions only during the peak of the epidemic, when wishful thinking acted as a positive and motivating response in the face of the viral threat [172].

All of the studies in my systematic review were conducted in Hong Kong, China and Singapore or Canada, covering the main geographical epicentres of the epidemic, but none assessed emotional responses and uptake of interventions in any high risk or targeted groups.

Discussion – The emotional determinants of the response to the SARS epidemic

During the peak of the SARS outbreak, fear and anxiety were rampant. The initial uncertainty, non-transparent communication, and misinformation about the disease further bred a climate of psychological distress. Whilst these fears were disproportionate to fears associated with other potentially fatal diseases, they naturally followed communications and disinformation from the authorities or media [274]. In this context, for some, anxiety manifested in “panic-buying” food, disinfectants, and other necessities, and in obsessive thoughts, restlessness, and feelings of panic. China and Hong Kong both reported incidents of individuals killing or abandoning pets because of fears of animal-to-human transmission due to local authorities and

state media accounts giving the impression that domestic animals were a local SARS threat. Other individuals engaged in compulsive behaviours, such as handwashing [274]. This context is a good example of how epidemic panic is often prompted not by disease threat per se, but by the social, political and economic forces that these threats expose [131].

In Hong Kong, 33.6% of residents worried that they or their family members would contract the disease [321]. Proximity to the outbreak and fear of infection spurred apprehension, helplessness, and horror. In addition to high rates of anxiety, Hong Kong residents in a telephone-based survey demonstrated high rates of psychosomatic symptoms including headache and dizziness [170]. One study found that 16% of residents exhibited signs of post-traumatic stress [174]. Quarantine measures further compounded emotional distress, as individuals spent time in isolation worrying about their personal risk while disconnected from the outside world [313, 173].

Various studies evaluated psychological responses among subsets of the population. In a study of university students in Hong Kong, anxiety levels were highest among medical students and those studying closer to the affected hospital [341]. A study comparing age differences in coping and emotional responses found that, during the peak of the epidemic, older adults felt less anger and were better able to regulate their emotions. Younger adults, on the other hand, demonstrated more emotion-focused coping (that is, stress management that attempts to reduce negative emotional responses that occur due to exposure to stressors) [342]. Another study examining the psychological impact of SARS on midlife women between ages 50 and 64, found increased distress and depressive symptoms during the outbreak. Common symptoms included feeling scared, restless sleep, and fear of financial losses [343]. Pregnant women, fearful of contracting SARS, overestimated their risk, with many isolating themselves at home [344].

Stress and psychological distress were widespread among frontline healthcare workers treating individuals with SARS in hospitals throughout Hong Kong. On self-administered questionnaires, 68% of these workers reported heightened stress. This pressure manifested as psychological distress among 57% of the frontline healthcare workers interviewed due to perceptions of their own vulnerability and a lack of support in the workplace [345]. In a survey of 180 Hong Kong Chinese SARS survivors discharged from a hospital, 35% reported “moderate to severe” or “severe” anxiety and/or depression on the Beck Anxiety Inventory and the Beck Depression

Inventory [346]. This distress was more common among individuals who had lost a family member due to the disease and those working in healthcare.

Despite evidence of psychological distress and impairment due to the fear and anxiety associated with SARS, it seems to be clear that extreme unpleasant emotions of fear and panic were often counterproductive, whilst anxiety and heightened sense of perceived threat did appear to be protective for many individuals by enhancing precautionary measures [168, 171, 169, 180, 175, 347]. Telephone surveys conducted with Chinese Hong Kong residents throughout the epidemic found that at the peak of the outbreak, residents actively absorbed media information on SARS and simultaneously demonstrated increases in preventive behaviours, including wearing masks, washing their hands, disinfecting their homes, and avoiding public places [168].

The perceived efficacy of preventive behaviours and perceived severity of the problem were associated with taking more precautionary action. In the Netherlands, individuals who perceived their risk of acquiring SARS as higher were more likely to display protective health behaviours [169]. While a study in Singapore found that higher knowledge about SARS did not sufficiently trigger precautionary action, anxiety was associated with positive health behaviours [171]. When it came to healthcare services use, a study in Hong Kong found that the most robust predictor of was the presence of symptoms in line with SARS presentation [175].

Worry and concern have also been linked to other prophylactic behaviours. Avoidance of symptomatic individuals, healthcare workers, and individuals assumed to be at risk for SARS based on either their travel history, relatives, or nationality was common [172]. In Hong Kong, individuals avoided those who had recovered from SARS, as well as individuals who had relatives who had contracted SARS or who lived in buildings with SARS patients. Reports described incidents of workplace-based discrimination, including firing these individuals [274].

In the face of globalisation and the increasing threat of infectious disease outbreaks, timely, effective, and realistic communication about risks and precautionary measures is essential [348]. This communication must account for the unique sociocultural and psychological factors in the community [349, 350]. By accurately conveying risks associated with an epidemic, emergency response teams can ensure adoption of healthy behaviours, particularly as higher perceived risk increases preventive action [171, 351, 352].

During the SARS epidemic in 2003, risk communication varied over time. In the early stages, Chinese and Hong Kong governments withheld information from the public. Delays in communication and a concentrated public health response fuelled an environment susceptible to super spreading events, and which threatened psychological, socioeconomic, and public health stability. Furthermore, early variance in discourse caused an uptick in public uncertainty and panic, and negatively impacted individuals' initial risk perceptions and compliance with recommended health behaviours [173, 353]. However, local governing bodies and international organisations ultimately collaborated to control continued transmission and provide accurate information to the public, leading to the WHO's eventual announcement that the outbreak was contained.

As the global population continues to grow, it is critical that we learn from the shortcomings in the emergence of and response to the SARS epidemic. Rapid detection and surveillance of new outbreaks, as well as co-ordinated national and international responses to communicate accurate information, and screen, diagnose, and isolate cases are vital. A 2004 meeting on lessons learned from the SARS outbreak discussed improvements in education, compensation for quarantined workers, advanced development of vaccines, surge capacity for vaccine production, and promotion of international collaboration [282]. By ensuring that governments and health authorities maintain crisis mentality, emergency preparedness, and timely communication, the physical, economic, social, and psychological repercussions can be managed more effectively.

H1N1 in Greece, 2009

Context

The H1N1 influenza pandemic of 2009-2010 was the first pandemic of the 21st century [354]. It presented a public health emergency of uncertain scope, duration and effect [355]. The global spread of the pandemic to almost every country brought the spotlight to the complexities in international cooperation, the difficulties in decision making under stress and wide uncertainties in the face of high risk, and the challenges in communication between experts, government, and the public [355, 356].

The new H1N1 virus emerged in humans first in Mexico and California, US, in April 2009. It was found to have a swine origin, as it was genetically related to viruses known to circulate among pigs for many years [354]. Even though initial transmission to humans may have happened months earlier [357], since spring 2009 the virus spread quickly internationally through human to human transmission [358]. The WHO declared a public health emergency of international concern on April 25th and subsequently raised the pandemic alert to the highest level 6 on June 11th. At that point in time, more than 70 countries had reported cases of the novel influenza A infection and there were ongoing community level outbreaks of H1N1 in multiple parts of the world. Children, young adults and those with an underlying heart or lung condition were disproportionately affected [359], with the highest case fatality rates recorded among the 50-60 year old population group [358]. A second wave of the pandemic was noted in late summer 2009.

The history of the emotional responses to this – generally seen as mild – pandemic is heavily influenced by the processes of trialling, approving and distributing medications and vaccines internationally, and people's attitude to them, especially in the follow up to the global economic crisis of 2008. Public health responses were closely intertwined with concerns about the economic impact and the state of different economies (including their states and governments) influenced public responses to public health measures and attitudes [360, 361]. Greece is an interesting case study in the context of this global pandemic. It has been a country hit particularly hard by the global economic crisis and suffered a disproportionately high morbidity and mortality burden of the H1N1 influenza waves since the beginning of the crisis [362].

On August 11th 2010, the WHO announced the end of the 2009 H1N1 influenza pandemic which saw a highly heterogeneous, both between and within countries, distribution of viral cases and

deaths [363, 364], and a legacy of increased scrutiny and mistrust in the processes by which healthcare products are regulated, promoted and distributed.

Epidemiology

Estimating the morbidity and mortality of the 2009 influenza pandemic is subject to many limitations since the laboratory confirmed deaths tend to severely underestimate influenza-related mortality because of the lack of routine tests in many countries and the difficulties in identifying influenza-related deaths triggered by other (bacterial) superinfections or exacerbation of pre-existing chronic illnesses [365]. At the end of the pandemic, the WHO reported that more than 214 countries and overseas territories or communities worldwide had reported laboratory confirmed cases of pandemic influenza H1N1 2009, and recorded 18,449 deaths [366]. However, modelling studies estimate the global death toll of the pandemic to have been at least 10 [367], or 15 times higher [368].

The data are equally – and perhaps even more – questionable for Greece. An enhanced surveillance system for pandemic influenza A (H1N1) virus was set up at the end of April 2009, led by the national public health agency, the Hellenic Centre for Diseases Control and Prevention (HCDCP) [369]. The first cases started being recorded in May and were associated with imported transmission (for example, students returning to Greece from abroad and foreign tourists) [370, 371].

Overall, Greece saw a moderate first wave during July-August 2009 and second winter wave in late October 2009, with a peak in the week of 23rd to 29th November. Another wave was noticed in March 2010 with cases falling down to zero by the middle of May [372, 373].

A small seroepidemiological study found a 28.5% overall seroprevalence rate [374], whereas a large household survey estimated the proportion of the Greek population to be symptomatically infected with H1N1 (based on influenza-like illness case definition) to be between 7.1% and 15.6%, with a true incidence of approximately one in five [375].

There were 141 deaths recorded in Greece due to the pandemic influenza A (H1N1) virus (which is likely to be an underestimation due to incomplete testing and recording outside of hospitals) [370], and which, though a low number overall, positioned the country as an outlier in Europe, with higher than expected relative fatalities [376].

Society and politics

The 2009 H1N1 pandemic occurred in a world facing multiple vulnerabilities that had been recently exposed at an economic and political level. The international responses to the pandemic revealed the difficulties that are inherent in decision-making under conditions of uncertainty, the complexities of global collaboration, and the challenges in communication between experts and policymakers, as well as the public [355]. The WHO provided some considerable leadership in the pandemic. It gave guidance to inform national influenza-preparedness plans, helped countries monitor their development of core capacities, through the Global Influenza Surveillance Network (GISN) it detected, identified, and characterised the virus in a timely manner, and monitored the course of the pandemic. However, the global agency also made a number of missteps in the course of coping with the unfolding pandemic [355]. This influenced the responses of different countries, many of which were struggling to deal with the consequences of the recent – and in many ways still ongoing at the time – financial crisis.

In this context, at the end of the noughties, Greece was, in many ways, in social and political chaos, underpinned by administrative structural insufficiencies, a dysfunctional bureaucratic public services system, a large shadow economy and extensive political corruption [377, 378]. Political polarisation was high, the economy was crumbling, a refugee crisis was underway, and demands for government modernisation were increasing; all creating tensions and a fundamental issue of governability [379, 380]. The causes of those circumstances went back several decades and had to do with issues such as the fiscal recklessness of the Greek state, clientelism and corruption, the populist practices of the Greek political parties, the inefficiency of the state machine, and the institutional and political problems within the European Union (EU) and the euro-zone [377].

In December 2008, some of the largest protests and riots in recent Greek history were started in Athens, following the killing of a teenager by a special police agent. They starkly revealed the latent frustration and resentment of the Greek youth at the time [377]. They were hardly unique. Throughout 2009 mass protests became the norm, as did consecutive strikes by public transport employees, discontent by farmers, as well as social unrest in relation to the treatment of asylum seekers and refugees. This sentiment and anti-establishment behaviour paved the way for the public response to the austerity measures that were to follow [381].

It was in this context of unrest, mistrust against the government and the authorities, and the “new emotional movement” in Greece motivating public participation in protests in response to troubling events [382], that the Greek government and public health officials were called to address the H1N1 pandemic in the country.

Economy

The history of and the narrative for this pandemic is closely intertwined with the 2008 financial crisis [361]. Soon after the global market crash, Greece was making headlines. The announcement by the newly elected Greek government in October 2009 that the projected budget deficit for 2009 was 12.7% of the GDP, rather than the 5.1% projected in the 2009 Spring Commission, was met with shock by officials in the EU [380]. It was revealed that Greece, which had taken advantage of the possibility to borrow promiscuously due to the lower interest rates its government bonds could attain, led by particular political parties for decades, had built up EUR300 billion in debt after the predictable strike of the global financial crisis. Unable to stand up to its financial responsibilities, it reached the edge of bankruptcy and, facing the fiscal debacle, resorted to social cost-cutting measures and heavy taxation, especially after the bailout proposal of the international leaders [380, 378]. The measures and pre-existing unrest fuelled an anti-austerity movement.

The fragile economy and corrupted politics were an explosive combination for the public health sector in Greece. Civil servants were able to use, politically sanctioned, discretion in, among others, public health and environmental checks, ignoring, for example, public health violations in exchange for a bribe [380]. The reality of the economic situation meant that an already underdeveloped public health sector became further underfunded and deprioritised in favour of tertiary services [378]. The economic crisis, a source of stress, shame, fear and anger for the Greek people at a macro-social level [383], was a key mediator of emotions at the time of the pandemic.

Healthcare and public health

The H1N1 pandemic prompted the first activation of provisions under the 2005 International Health Regulations (IHR), which went into effect in 2007. These regulations outlined the

responsibilities of individual countries and the leadership role of the WHO in declaring and managing a public health emergency of international concern [384]. However, response across different countries was not consistent.

Antiviral drugs were made available since April 2009 – with some countries stockpiling large numbers – with the WHO issuing guidance in August [363]. However, a review published in December 2009 highlighted that there was not sufficient evidence for or against the commonly used neuraminidase inhibitors for treating influenza complications [385]. The accompanying investigation drew attention to the processes by which drugs are regulated and promoted, on the back of the public evidence base for this global public health drug being inconsistent and fragmented [386]. The first H1N1 influenza vaccines were approved by the Food and Drug Administration (FDA) in the US in September 2009 and in late December 2009 H1N1 vaccination had been opened up to anyone who wanted it [364]. The experience was that the pandemic vaccines were successfully developed and deployed, but access was unequal as they became available in significant quantities only after the peak of the viral infection and only in high-income countries [387, 388].

The pandemic found Greece's healthcare system in disarray, lacking the setting of common targets recommended years ago [378]. At that point in time, Greece's health system was a mixture of public integrated, contract and reimbursement models, comprising elements from both the public and private sectors and incorporating principles of different organisational patterns. Access to services was based on citizenship and occupational status. The system was financed by a combination of state budget, social insurance contributions and private payments [389]. Unlike its initial design, the system had evolved in a fragmented manner leading to inequitable access to health services, conflicting incentives for providers, escalating costs and corruption. The lack of ability – or for many complicity – among a series of Greek governments to stem the predatory behaviour of powerful elites to benefit financially from the state resources, including in healthcare, is a well recorded problem [380]. The economic crisis came to aggravate the situation further [390] and certain proposals about a more rational, evidence-based, and integrated system had failed [378, 391]. These structural issues were heavily contributing to an increased burden in both communicable and non-communicable diseases [378].

Vaccination against H1N1 in Greece was initiated at the end of November 2009, with the intent at that point to ultimately administer the vaccine, with no charge, to anyone who wished to

receive it. In the first instance, vaccination was offered to healthcare workers, with people at high risk of influenza-related complication next, and then healthy adults older than 50 years of age. Despite the objective of widespread coverage, at the end of February 2010, only 3.2% of the Greek population had been vaccinated against 2009 H1N1 [392], one of the lowest rates in Europe and in the world [393].

In fact, the Greek government provided a loan of EUR200 million to the HCDCP for the purchase of pandemic vaccines. Using EUR120 million of this fund, 16 million doses were ordered (for a population of approximately 10 million) in September and October 2009 [394], with an investigative newspaper article a few years later revealing that the actual initial order might have been even bigger, 24 million doses [395]. Usual vaccination programme activities were not successfully implemented because of confusing information provided [396], and due to low uptake it was decided later that the order for 8.3 million for those vaccine doses would be cancelled (following a legal challenge). The Greece state was eventually left with 3,799,590 doses of pandemic vaccine and ended up distributing less than a tenth of those (and less than 3% than the initial order), only 364,559 [396, 394].

A combination of underinvestment, corruption, fearmongering and lack of transparency, led to very low levels of trust by the people of Greece towards their government and health agencies. The non-systematic response and the unhelpful role of the media made things worse. At the early stages of the pandemic well known physicians were arguing on national television about the severity of the infection, and later about the safety profile of the H1N1 pandemic vaccine. Schools closure was implemented sporadically and only after the peak of the pandemic with no concurrent measures. In the means of public transport in Athens, a pre-recorded message was played in a loop warning of the pandemic and urging users to keep the train or bus windows open. However, for trains and the metro (the busiest means in the city), this coincided with works on the electric railway lines that led to the trains being less frequent than normal and coaches being severely overcrowded [397].

Culture

The 2009 H1N1 pandemic is one that felt highly disconcerting at the time and almost unimportant in retrospect [398]. From a cultural perspective, a study of the media hype is

particularly interesting for this pandemic given extensive coverage and its position in history as the first global pandemic occurring in a highly interconnected online world.

A systematic review on the issue of media coverage of the pandemic found that it received huge media attention (though not parallel to the trajectory of the pandemic) and the majority of research did not identify evidence of media dramatisation. However, some of the evidence for the latter has been conflicting and varied on account of differences in the epidemiology, media systems and local news cultures [398].

For a more direct assessment on Greek media, I undertook a systematic search in the archives of the five highest circulation daily newspapers, using keywords (translated in Greek) such as “H1N1”, “pandemic”, and “influenza” in the article titles, between January 1st 2009 and December 31st 2010. It is anticipated that articles would have been missed due to limitations in the text search capabilities, nevertheless a total of 1,744 articles were identified (Table 4.1).

The majority of the coverage was focused on the epidemiological characteristics of the pandemic as well as general information about the pandemic (predominantly reproducing translated content from the WHO) and the vaccine development, testing, safety and distribution. One in five articles identified were not considered informative or factual, rather journalistic analyses or viewpoints. After separating those that were focused on the economic effects or financial, a total of 324 articles remained. Based on an existing coding framework, [399] these were classified as either “alarmist” (those that were judged as potentially able to trigger anxiety for the reader), or “reassuring” (potentially able to allay the reader's fears).

Alarmist articles were five times as common as the reassuring ones. Sensationalist headlines featured heavily in those “serious” newspapers, declaring the “Decade of Fear” [400], asking for “God’s help” [401], or projecting that by autumn 2009 the whole country would resemble a vast hospital [402]. Interestingly, the plethora of alarmist articles and conflicting information communicated by the media led the Greek National Council for Radio and Television to issue a statement urging journalists to not broadcast unsubstantiated information about the pandemic and to champion a sense of responsibility and calmness to help prevent confusion and panic [403].

Table 4.1. Articles about the pandemic in the five biggest Greek newspapers.

	General	Vaccines	With health expert s	Epidemio- logy	Econ omy	Alarmist	Reassuring	<i>Total</i>
Eleftherotypia	221	103	16	305	20	108	17	<i>790</i>
To Vima	94	45	21	129	7	59	13	<i>368</i>
Ta Nea	95	36	11	126	2	55	9	<i>334</i>
Kathimerini	59	16	6	30	5	28	13	<i>157</i>
Ethnos	25	6	1	36	5	20	2	<i>95</i>
<i>Total</i>	<i>494</i>	<i>206</i>	<i>55</i>	<i>626</i>	<i>39</i>	<i>270</i>	<i>54</i>	<i>1,744</i>
<i>Proportion</i>	<i>28%</i>	<i>12%</i>	<i>3%</i>	<i>36%</i>	<i>2%</i>	<i>15%</i>	<i>3%</i>	<i>100%</i>

Greek media seems to have been disproportionately alarmist in their coverage of the pandemic compared to media in other nations [404]. An international review showed that most of included studies did not find evidence of media dramatisation but concluded that news reporting was mostly factual and non-alarmist [398], as seems to have been the case in countries such as the United Kingdom [399] and the Netherlands [405]. There is, however, some evidence from this pandemic in France that immense and alarming media coverage led to antibiotic overconsumption [406], and it is reasonable to assume that Greek media played a role in influencing the public's emotional responses and healthcare behaviours during the pandemic.

This counterproductive influence was not born in a vacuum, nor was it the result of the pandemic. The Greek media system has been analysed and critiqued in the scientific literature. It is subject to several limitations due to high political parallelism, weak professionalisation of journalists, instrumentalisation of journalistic work by external agents, and a strong role of political parties in combination with a weak regulator [407]. Since the late 1990s, newspapers

have become less economically viable and the Greek citizen’s right to information is considered to be under threat [408].

The role of the media was one theme that was critiqued in the satirical cartoons of the time. Political cartoons have regular spots in Greek newspapers. For example, in Figure 4.5, a female patient asks her doctor: “Doctor, what kind of steps should I take for the flu?”, which prompts the response by the doctor: “There’s only one medicine! You need to cut down on the News”. In Figure 4.6, a wife asks her husband: “And how is this swine flu transmitted?”, with a response of “Up to now, it’s been spreading between journalists”.



Figure 4.5



Figure 4.6

The combination of the news around the pandemic with the economic crisis favoured a variety of satirical comments by both well-known and emerging Greek cartoonists.

In Figure 4.7, a crowd of patients is congregated in a pharmacy with the desperate pharmacist asking if they are all looking for vaccines. The crowd responds that they are there to have anti-stress medication. In Figure 4.8, a stereotypical Mexican caricature patient asks a fellow stereotypical Greek caricature patient: “Is it the flu for you as well?”, with the Greek patient responding: “No, it’s the scandals”.

In combining imagery with narrative and capturing the attitudes of the era, cartoons are both able to trigger an emotional response and to reflect some of the emotions of that period [409].

NEA γΡΙΠΗ !...



Figure 4.7



Figure 4.8

Emotions around the H1N1 pandemic in the literature

Influenza is the most common infectious disease with the capacity to cause epidemics and pandemic, thus, unsurprisingly it was the most studied infection in my systematic review. A total of 31 included studies looking into the issue of public emotional responses and uptake of public health interventions, covering a range of countries and locations across all continents except South America. Twenty-six of those focusing on the H1N1 pandemic (the others on H5N1 and H7N9 outbreaks), the vast majority of which (N=22) were published between 2009 and 2012. In all, 40 correlations between an emotion and an outcome were attempted in the studies.

Feelings of worry and anxiety about H1N1 were the most frequently studied, with significant evidence that these moderate anxiety-related emotions had a positive effect on the uptake of public health interventions in the settings studied. Twenty-two out of 28 correlations showed taking of action on uptake of interventions (p=0.004).

Contrary to this and the case of SARS, a large high quality cohort study of 12,965 people from Hong Kong found that anxiety levels were not associated with increased knowledge on modes of transmission or improved adoption of hygiene measures [182]. Greater anxiety was only associated with greater social distancing. This is in contradiction to the evidence from the SARS epidemic in Hong Kong [175, 347], and this connection is interesting in this case, as, in this study, perceived severity compared with SARS was initially very high but declined sharply during Spring 2009. The experience of the recent SARS epidemic is likely to have played a role in how Hong

Kong residents responded to the H1N1 pandemic and highlights the need to take local context into account when designing public health communications evoking emotions.

A campaign evaluation from Australia did not find an association between anxiety in the public and a willingness to be vaccinated. However, it was noted that media and government communications were most likely not effective in creating “enough” anxiety and concern amongst the public and reinforces the notion that the public considered the virus mild and vaccination perhaps unnecessary [198].

In only two out of nine cases when more extreme emotions (panic and fear in the case of H1N1) were evoked was there an association with uptake of interventions, though the overall finding in my review was not statistically significant ($p=0.179$). Evoking the emotion of fear was, in fact, not even found to be effective in a sample of high risk patients (those with rheumatic diseases) in a cross-sectional study in China; fear did not increase willingness to receive vaccination [187]. In a qualitative study of pregnant women in Morocco, intense emotions of fear and panic, expressed as extreme anxiety about the vaccine, fear of death and miscarriage, or deeply held conspiracy theories, were counterproductive, influencing non-acceptance of the pandemic vaccine [203].

The pleasant emotion of empathy was assessed in a high quality cross-sectional study of 100 residents in the city of Dharwad in India. It found that people who responded to the risk of H1N1 with greater empathy were, independently, more likely to adhere to recommended public health measures, such as vaccination and handwashing). The study identified a synergistic effect of empathetic responding and perceived threat, i.e. when the empathy responding was high, an increased threat perception was associated with a higher chance of adhering to recommended health behaviours whereas perceived threat had no effect when empathy was low [208].

Discussion – The emotional determinants of the response to the H1N1 pandemic

The 2009 H1N1 pandemic was the first of the 21st century, following an interpandemic period of more than four decades. Some fascinating evidence is available in relation to the H1N1 pandemic that helps push forward the understanding of the role of emotional determinants. The “emotional epidemiology” of this pandemic has been recorded and described well, especially in relation to the race of developing and making a vaccine available. In several

countries, the public went from a flooding of fear to a demand for a vaccine, and from panic and exhaustion to suspicion and indifference [410].

Despite being overall characterised as “mild”, it has brought substantial learning, being the first pandemic when media and social media messaging challenged conventional public health communications [411].

Gaining a nuanced view of audience insights is fundamental to creating appropriate health communications that address emotional determinants. However, not unlike the cases of other infectious disease outbreaks, most countries did not conduct any audience research or co-production to inform the content, design, tone, targeting and emotional appeal of communications provided to the public [412]. A mindset of emergency and rapid response from government and health officials has been cited as the reason for the lack of such participation, which did lead, though, to “top-down” and “one-size-fits-all” communications of questionable benefit, exposing a lack of a cultural norm and infrastructure in many nations to carry out such participatory work [412].

Research around the H1N1 pandemic was global, rapid and diverse. It allowed the gathering of evidence to understand better some key factors that encourage uptake of recommended behaviours. In the context of emotions, a systematic review showed that greater levels of national or state level anxiety as well as greater trust in authorities were associated with the adoption of recommended behaviours [413]. This is consistent with the findings in my systematic review and research on influenza prior to the pandemic which has shown that considerable proportions of the population (between 20% and 35%) are worried about them or their families contracting the flu [414], which leads to several preventative behaviours, including hand washing, vaccination, or avoiding public places when there is an outbreak [413]. However, such responses are apparently declining over time and their consistency can be influenced by media coverage [415].

The role of the media in the H1N1 pandemic has been studied in more detail than in other cases. The WHO Director-General said that the media was a contributing cause of heightened risk perception among the public [416], while some public health scholars went further to call the 2009 pandemic an “*iatrogenic pandemic of panic*” [417]. International research, however, has not necessarily supported this view, at least for certain high-income countries where coverage was not assessed as overly dramatising or fearmongering [398]. Greek media, on the other hand, seem to have been disproportionately alarmist in their coverage of the pandemic [393].

The coverage from the media of the pandemic was certainly immense and, rather unhelpfully, did not follow the trajectory of the pandemic (that is, reflecting the number of cases) [398]. Where coverage was more sensationalist and more enduring (especially in the cases that it was event oriented and not driven by the spread of the infection) though, it did influence the public's emotional responses, increasing feelings of fear first, while later leading to indifference [418, 419, 420].

This journey from fear and panic to indifference and apathy seems to be the key emotional trajectory of the public in Greece in this pandemic. This is supported by a study of perceptions, emotions and responses in the island of Crete during the pandemic which showed that higher levels of worry and manageable fear at first were associated with self-protective actions, whilst detachment at later stages was linked to avoidance of carrying out any preventive action because the risk of infection was considered low and it was felt that there was not much at stake [421].

My systematic review showed that these extreme unpleasant emotions are counterproductive when it comes to motivating uptake of interventions of behavioural change. This can – at least in part – explain how Greece ended up with one of the lowest vaccination coverage rates and one of the highest annual rates of influenza mortality in Europe in 2009 [422], and suffered an even higher burden of H1N1 cases and fatalities in the subsequent influenza seasons [423].

These outcomes in Greece were not born out of a vacuum and these emotional responses were not shaped out of the blue. As my study and other research shows, they are the result of both long- and short-term social, economic and political forces, including, among other factors, Greece's position in the world, the start of the economic crisis and the response to it, the state of the government and the public's trust in it. The attitudes towards the pandemic in Greece are consistent with the attitudes at the time towards the government, and politics more generally, which included a mixture of political distrust and alienation [377]. The low uptake of public health interventions was further due to the way in which mass media handled the pandemic news and the vaccination effort, focusing on government scandals and safety concerns rather than the preventative value of measures [424]. And the media's inadequate coverage was a result of pre-existing systemic cultural issues, further aggravated by shortcomings in the communication strategies by the relevant Greek authorities [408, 424].

The systemic issues in Greece impacting on the emotional responses and uptake of interventions persisted for several years. By the end of 2011, a year later than the official end of the pandemic,

Greece had seen a disproportionately high morbidity and mortality burden of different epidemics (also including West Nile virus, malaria and AIDS), and heavy cuts in health spending as part of the austerity measures [362], as well as persistently low flu vaccination coverage [424]. In this context, Greece remained one of the most interesting and important case studies in Europe on the emotional responses of the public to government and international measures throughout the 2010s.

Ebola in West Africa (Guinea, Liberia, Sierra Leone), 2014

Context

The Ebola Virus Disease (EVD) outbreak in West Africa in 2014 was the largest ever recorded of its kind [425]. The outbreak tested the world’s global ability to address a humanitarian issue that had the potential to become a global pandemic [426], and put the spotlight on the importance of reducing the vulnerability of societies to infectious disease threats that spread across national borders [427].

Since the virus’ first description almost four decades before [428], all outbreaks had been rare, localised in rural areas and small [425]. This was an outbreak that occurred in a low resource setting, spreading to urban centres in a deadlier form than ever before, of a disease the standard treatment for which had not changed in the past 40 years [429]. Interruption of its transmission required rapid identification of cases, contact tracing, and monitoring of people identified as high risk [430].

The epidemic spread from an index case of an 18-month old boy from a village of southern Guinea, who was infected by contact with bats in December 2013, and his family [431]. The epidemic reached the nation’s capital in March 2014 and the causative agent was confirmed as the *Zaire Ebolavirus* later that month [432]. The outbreak was officially declared by the WHO on March 23rd, with 49 confirmed cases and 29 deaths [432], and it subsequently grew exponentially between June and September in Guinea, Liberia and Sierra Leone, where the national case number was doubling every 16 to 30 days [433].

International interest in this outbreak did not really gain momentum until two American healthcare workers became infected in Liberia in July, a fact that triggered a fear, further exacerbated by the role the media played in conveying information, that the epidemic would escape the African continent [434].

In August 2014, WHO gave the epidemic in West Africa a Public Health Emergency of International Concern status, assigned to events requiring a co-ordinated international response. This lasted to March 2016 as cases started to decrease from the middle of 2015 [435]. Liberia was declared Ebola-free in January 2016, Sierra Leone in March 2016 and Guinea in June 2016 [425].

This 2014 outbreak of “*an old virus in a new context*” in West Africa [432], is thought to have exposed important deficiencies in the ability and capacity of the international scientific and

public health community to respond to such epidemic emergencies [425], and has generated valuable learning on the emotional determinants.

Epidemiology

The epidemiological dynamics of the epidemic were challenging to understand initially, as the high mortality rates meant issues such as the safety of healthcare workers needed to be prioritised [103]. The epidemic attracted the attention of the international public health and infectious diseases community, and became a major news issue in the United States. However, it is important to note that it was largely restricted in the three nations of West Africa: Guinea, Liberia, and Sierra Leone. A total of 28,656 cases were reported (and 11,325 deaths), of which only 36 were in nations outside of those three, with 20 of those in Nigeria and eight in neighbouring Mali [435].

A main factor for the emergence of the epidemic seems to have been the deforestation of the Forest Region of the Gueckedou District in Guinea. Foreign mining and timber operations led to loss of more than 80% of forest, bringing wild animals and bats (the natural reservoir of Ebola virus) closer to human settlements resulting in the contact of the index case with insectivorous bats in his backyard [432].

This outbreak seems to have been larger in geographical spread and cases contracted for several reasons [432, 435]:

- (i) It was the first time ever that EVD spread in crowded urban areas, and especially of low resource and poor public health infrastructure (this also meant that early detection and relevant clinician expertise were poor).
- (ii) Local social determinants were important, including the damaged infrastructure and the lack of education in the three nations that had only recently emerged from years of civil war.
- (iii) There was high mobility of people across porous country borders.
- (iv) There was some conflict between international infection control practices and local cultural and traditional practices (including unsafe burials and contact with dead bodies).

- (v) The local surveillance systems were weak.

The spread of the virus was eventually contained thanks to increased engagement with local leaders in prevention programmes and careful policy implementation at a local and international level [425, 435].

Society and politics

The WHO was widely criticised in 2014 for not providing a decisive, early response to the Ebola outbreak [436]. An international debate has highlighted that the WHO failed to strengthen its local emergency support and outbreak control, and only did so when the epidemic had already been “*out of control*” [437]. Several reasons had been provided for this, including underfunding for tropical emerging infectious diseases [438], gaps in the leadership and governance issues in the organisation’s headquarters [439], political relationships including a lack of willingness to declare an emergency as it would have consequences in the local economy [440], trading and international business in relation to the affected countries [440], and a general underestimation of the capacity of the virus to cause such widespread damage [436], especially in urban settings.

The global context of health security underpinning those though, is even more complex. Once critical in making global health more prominent in world affairs, the global health security strategy had, by the 2010s, suffered political neglect by countries – and subsequently downgrading within the WHO – well before the first case of Ebola in West Africa [441, 427]. Although several nations stepped in and responded when the Ebola outbreak escalated into a crisis, the scale of the tragedy and the surge of need and demand for a response, highlighted the lack of political commitment that has been noted before the outbreak [442].

In the face of the international lack of direction, local leadership in the three nations affected played a critical part in addressing the crisis (Figure 4.9). Whilst the first phase of the epidemic was hampered by insufficient attention to sense-making and weak decision-making, in part because of the existing hierarchical leadership approach, the old hierarchies were replaced by a distributed leadership approach in subsequent phases [443]. This enabled sharing responsibility and authority, strategically engaging stakeholders and communicating intensively [443]. This approach left local leaders empowered to combat misinformation, especially in the latter phases and the long tail of the epidemic [444].

Empowered and culturally appropriate local leadership is critical in the long tail of the epidemic and the future rebuilding of the local communities, especially since, from a societal perspective, the epidemic had a big impact on children and young people from several dimensions. As many as one in five cases of EVD were among children under the age of 15 years old, whilst a total estimated of 30,000 children became orphans during the epidemic [445]. With some of the funding and resource allocation to child vaccination programmes shifting to the response to Ebola, routine vaccination rates dropped by 30%, which meant hundreds of thousands of children became at increased risk of preventable infectious diseases [425]. Further, the number of pregnancies dropped given the high risks of haemorrhage and contagion [425].

Economy

Prior to the epidemic, healthcare in the three predominantly affected nations was severely underfunded. Data from 2012 show that the Guinean government spent \$9 per person per year on healthcare, the Sierra Leonean \$16, and the Liberian \$20. All were far below the recommended by the WHO minimum of \$86, necessary to provide essential health services [446]. Health systems in all three countries lacked the funding and capacity to expand care to all at the point of need. The epidemic stretched them further and even following the end of the emergency, many survivors had to wait months to undergo surgery for cataract and others were re-traumatised as they were being re-tested for Ebola at the point of admission [447].

The region was only starting to recover from years of civil war and poverty, damaged infrastructure, and lack of education were common [432]. War and famine are well recorded determinants of epidemic emergence [448], as identified in my contextual review as well in Chapter 2. Particularly in the three affected nations, the epidemic heavily contributed to declining economies, closed borders and markets, exacerbation of poverty and widespread hunger [449].

The Ebola outbreak illuminated not only the value of protecting people's lives through disease control, but also of the importance of strong healthcare systems in a prosperous economy and peaceful society. It was a reminder that the world had failed to share the benefits global economic growth, leaving the West African societies without appropriately resourced healthcare systems, and, hence, vulnerable to the effects of Ebola [450].

Healthcare and public health

Following the slow start and the realisation of the fact that the available local resources were low, the international response to the outbreak was strong. By the spring of 2015, there were 176 organisations operating emergency programmes in Guinea, Liberia, and Sierra Leone reaching a point where the total number of Ebola Treatment Unit beds exceeded the number of reported patients and enough safe burial teams were also in place [425, 451]. However, the distribution of these resources was not adapted to the geographic spread of Ebola and the international community did not take care to start from addressing the continued fear and suspicion of Ebola treatment hospitals and burial teams in local communities. These resulted in many patients still going without treatment or safe burials which led to new infections [451].

An additional public health measure that further added to the local controversy and suspicion was the enforcement of mass quarantines. All three affected nations implemented quarantine in large forest areas around their shared borders [452]. The Liberian government went further to implement a 10-day quarantine in August 2014, enforced by soldiers in the country's largest slum, West Point, housing approximately 75,000 residents [453], whilst the Sierra Leonean government implemented a three-day nationwide mass quarantine in September 2014 in an effort to find patients hiding across the country [454]. These measures came in an environment where the international recommendations were not clear, and no effort had been made to engage the local communities. The result was further uncertainty, voices calling the measures a violation of rights to liberty and security [455, 452], and an intensification of the phenomenon of people exposed to Ebola hiding from healthcare services [456]. These would have certainly exacerbated the anxiety and fear in the local populations as quarantine was fundamentally associated with loss of personal freedom, and the violent enforcement of it using military troops, in an environment of mistrust, further alienated the very people who would ideally be engaged in the response [452]. The issue of quarantine sparked debates and legal cases in other places as well, including the US [457, 458].

Despite the perceptions toward healthcare workers which varied widely during the epidemic, it should be noted that the outbreak had a direct significant impact on healthcare human resource. Healthcare personnel called to care for people with Ebola were among those at highest risk for contracting the infection. In fact, during the epidemic, Liberia lost 8% of its doctors, nurses, and midwives to EVD [459]. In addition to these devastating effects on the workforce in Liberia, Sierra Leone and Guinea, the epidemic had a severe impact on the provision of healthcare

services and caused setbacks in the treatment and control of tuberculosis, malaria, measles, and HIV in these countries [460]. In a vicious circle, the risks to health worker's health security, meant that Ebola-infected West Africans had to accept that health care was not always safe, not always effective, and not always accessible, and, hence, their own health security was always at risk [427].

Vaccine trials started soon, including two studies in Ghana. However, these exposed the role of rumours in spreading uncertainty, fear and distrust, causing controversy and a dispute between health authorities, political actors and the public which escalated to the point of the trials being suspended [461]. The main concerns, as communicated by claims made in the media, were that the vaccine trials would cause an Ebola outbreak in Ghana, and the incentives offered to participants were compensation for the trials' risks which included that the vaccine might give study participants Ebola as a side-effect [461]. As mentioned earlier, Ghana was a setting where knowledge of Ebola was low and misconceptions were persistent. For example, fear locally was exacerbated by the fact that huge colonies of fruit bats (which were thought to be a host for EVD) existed in the country and restrictions were being imposed on the consumption of bushmeat, which was a local delicacy [426].

Culture

The Ebola epidemic brought desperation and devastation to local communities. The nature of the direct transmission of the disease brought particular challenges.

It was noted that several funeral and burial practices in West Africa are considered as exceptionally high risk from a public health perspective. This includes mourners bathing in or anointing others with rinse water from the washing of corpses, especially in Liberia and Sierra Leone, or people sleeping near corpses for several nights believing that this practice enables the transfer of powers [432]. In the first year of the epidemic, as much as 60% of cases in Guinea were linked to these traditional practices [425].

However, it was not just burial practices that presented a challenge. Simple everyday actions, such as caring for loved ones in the family home, parents holding their children who were ill, or nurses compassionately touching their patients frequently led to transmission of the virus and the instructions from public health professionals to reduce human contact brought alarm and hopelessness [462].

In this context, when Ebola started spreading faster and more widely than anticipated, the WHO and other agencies delayed the deployment of responders to West Africa, driven by the local fear. A contributing factor to this delay was early media reports from Guinea and Liberia which were misleading and heavily framed Ebola as a highly infectious condition causing terrifying symptoms [436]. This spread to places further away, such as Ghana where during the first six months of the epidemic communications solely focused on a strange disease confined in rural areas with no prevention strategies [426]. Communications that were heavily using medical terminology and focusing on fear led to both panic in other African nations because of the possibility of transmission through air travel [463] and suspicion in the affected areas.



Figure 4.9. Marie Claire Tchecola who received the State Department Women of Courage Award in 2015. She was exposed to EVD while caring for a patient at Conakry's Donka Hospital, Guinea, in July 2014. Once she identified her symptoms, she checked herself into a treatment centre, stopping the chain of transmission. Despite being forced by her landlord to leave her home, once recovered she returned to her caring work at the Hospital. She became an active member of the Ebola Survivors Association of Guinea, spreading awareness about the disease. Photo credit: State Department. No copyright, public domain.

Communities in the three affected nations were not convinced by the media-driven image of Ebola [436]. In Liberia, especially, these communications and the quarantine measures reinforced rumours that the outbreak was a measure taken by the government in an attempt to manage population growth and attract international funding [426]. The real motivations of the

foreign medical teams were questioned in all three countries and this social resistance was further aggravated when bans on traditional burials and limits on social interactions were introduced [436].

The misunderstandings, the suspicions, and the deadly nature of the condition gradually started to bear a considerable stigma against people showing symptoms, perceived as exposed to the virus, and the healthcare workers. Touching someone could make people sick [447]. Ebola became the new AIDS, where whole groups of people were shunned due to a toxic mix of scientific ignorance and fear-based communications [457].

This stigmatisation extended globally to encompass in the eyes of international communities the whole of the countries with widespread Ebola infections and, in fact, the whole of the African continent [449]. The media hype, the generic use of “Africa” and “Ebola” in the coverage of the epidemic, and the persistent lack of understanding and engagement from some parts of the world with the geographical and cultural differences and nuances of the various African nations, led to a wider ecology of fear impacting perceptions around the world (Figure 4.9).

A concern that the Ebola crisis might trigger large scale migration, which in turn would enable further spreading of the virus, emerged. Several neighbouring countries closed their borders, remote countries, such as Australia imposed temporary visa restrictions, and several airlines reduced flights to the affected countries, or, in some cases, to the whole of the African continent [464].

This was particularly harmful to the tourist economy, which is a big driver of development for certain parts of Africa, that saw a universal drop in visitors despite a complete lack of risk of exposure to Ebola (including an over 50% loss in safari bookings for the year 2015). A specialist travel agent advocated for tourists to not fear a holiday in most African nations, using epidemiological evidence and images to try to clarify the risks (Figure 4.10) [465].



Figure 4.10. "Adventure Life" specialist travel agent tried to explain how low the risk of exposure to Africa is in many African nations advocating for more holiday in southern and east Africa.

Despite evidence from previous health crises showing that travel bans do not always work and their unintended consequences mean that they are sometimes more harmful than beneficial [466], restrictions were imposed. Influential figures, including the future President of the US, Donald J. Trump, took to social media to demand air traffic control (Figure 4.11), only adding to the global panicked reactions.

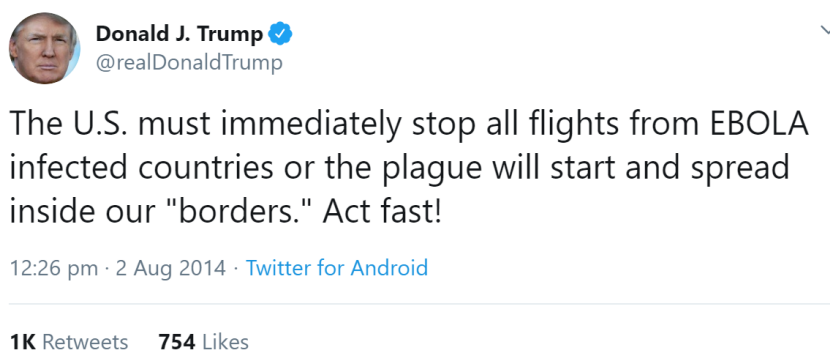


Figure 3.11. Post on Twitter by Donald Trump demanding air traffic control to stop the spread of Ebola.

Emotions around the Ebola epidemic in the literature

In the face of the early and persistent denial that Ebola was real, health messages issued to the public repeatedly emphasised that the disease was extremely serious and deadly, and had no vaccine, treatment, or cure. While intended to promote protective behaviours, these messages had the opposite effect and fuelled hopelessness and despair [432].

This was also identified in my systematic review. There were five studies (four of which were of high quality) attempting seven correlations on whether emotions evoked during the Ebola outbreak led to protective action taken by the public, although only one of these studies was conducted in one of the affected nations (Sierra Leone, in which feeling fear was a barrier to taking action) [210]. In six cases, *fear* and *panic* were evoked and these did not lead the public to take any prophylactic measures (such as following personal hygiene methods and staying at home) or increase their knowledge [207, 209, 211], a statistically significant result. In fact, fear and panic proved to be counterproductive and a barrier to taking appropriate action [210, 211], whilst in the case of some Nigerian bushmeat handlers (in a low quality study, though), panic associated with conspiracy theories meant that no effort was made to improve meat hygiene methods [207].

Interestingly, the biggest part of the research on the Ebola outbreak and emotions – and most notably fear – comes from the US where the scope of the epidemic was very small and there were only a few cases, but public health communications and preparedness are more advanced. A qualitative study found that a range of unpleasant emotions, including fear, anger, anxiety, disgust and sadness, were positively related to the US's public perceptions of risk about the EVD outbreak. Such emotions were not conducive of protective behaviours. In fact, fear was shown to be counterproductive in allowing systematic processing of the relevant information about risk and its subsequent influence on acting on institutional mitigation measures [5].

Beyond the US, a high quality study in Spain showed that whilst participants saw the outbreak as inherently African, they also expressed fear of it as a global threat and anger at political governments and media for failing to adequately manage the crisis [467]. In one high quality study in Germany, the more moderate emotion of *worry* was evoked and led to the public pursuing additional education about the epidemic [216]. A sign of the increased interest in emotions in this epidemic was that one of the studies developed an “Emotional Response to Ebola Scale” which included items on worry, fear, panic, depression, helplessness, distress and fluctuating emotions, with ratings on each. However, the study only attempted to correlate an

overall score to public knowledge and misconceptions, and did not assess whether emotions determined behaviour [209].

On the other end of the spectrum of emotions, compassion seems to have played a role in enabling the spread of the EBV. This might seem contradictory to my systematic review which suggested that pleasant emotions (mainly empathy and hope) tend to play a positive role in motivating prophylactic or other action by the public in response to an outbreak. However, in this case, compassion is not meant as an emotion felt in response to a public health communication or other trigger, rather as a cultural trait. In its year-one report on the epidemic, the WHO noted that Ebola virus seemed to have spread through networks bonded together by a culture encouraging compassionate care for the ill and ceremonial care for the deceased's body. There also existed records of doctors most likely getting infected because they rushed to aid patients who collapsed in waiting rooms or outside hospitals with no hygienic protection [432].

Discussion – The emotional determinants of the response to the Ebola outbreak

Several sources and mentions have established the West Africa Ebola outbreak as one where fear and panic spread quicker than the infection [468]. The world was terrified, concerned and alarmed by this disease in a way that had not been seen in recent history.

The responses of healthcare providers contributed to this. When patients were taken to treatment or transit centres, anxious families often received little information about the patient's condition, outcome, or even the place of burial [432]. In other cases, such as in Monrovia, Liberia, when Ebola was identified as the causative agent of the epidemic, several members of staff left the hospital in fear [447]. The threat of the virus was overwhelming to the local communities, and until mid-2014 no-one could conceive that it was possible to beat the epidemic [462].

For the public in West Africa this narrative meant that if hospitals and international aid were not able to offer any treatments or therapies, families preferred to care for their loved ones at home, or in some case even hiding patients in their homes. In their view, if death was almost inevitable and the hospitals were not transparent, they should be letting this happen as comfortably as possible at home, among familiar faces [432].

Subsequently – but perhaps too late for thousands of families – several experts noted that in the case of the Ebola crisis, the well-studied issue that control efforts must work within the culture, not against it, emerged. When technical interventions cross purposes with entrenched cultural practices, culture always wins [432].

The response to the outbreak started becoming more effective in turning the tide once the international efforts became more focused and professionals started co-operating with local communities. Anthropological observations showed that the treatment of Ebola had strongly focused on the biomedical aspects alone and disregarded parameters such as community, society, and culture. Consequently, they started to take the emotions – expressed as fears and concerns – and traditional beliefs of the members of local communities seriously [469, 470]. Hope, education, and local communities and healthcare practitioners working together were decisive factors in tackling the epidemic, compared to the earlier stages when hopelessness, panic and desperation were dominant [462]. The failure to adopt community engagement methods and take emotions into account was initially neglected, yet eventually proved effective in winning the trust of rural populations [436].

Ebola drew a certain *ecology of fear* around it. The term “ecology of fear” seems to have been popularised by American author and historian Mike Davis and his 1998 book on the interaction between natural hazards and social contradictions of Los Angeles [471]. In a similar way as Davis’ book described that the response of the city, public and industry of Los Angeles to environmental risks is a media-induced denial – that is, a socially constructed emotional response more dominant than the actual present risk – the Ebola outbreak in West Africa triggered a collective fear that spread internationally, almost completely dis-connected to the epidemic’s actual capacity to spread.

After the American media became interested in the epidemic, a fear of it escaping the African continent spread faster than the actual virus [434]. There is an ecology to this spread of fear that requires a more holistic understanding. Despite the wide criticisms of the WHO for the slow response in the early stages of the epidemic, the more nuanced study of the role of emotional determinants, along with existing historical critical analysis [436], suggest that perhaps the solution to better preparedness and response is not so much in altering the managerial procedures at the WHO or refining the triaging of emerging infectious disease (EID) risks. Following identification and research for several decades, by 2014, Ebola had become an object of medical and political neglect as it was largely seen as a rare disease of remote forested regions

of central Africa [436]. This was in the context of a wider international political neglect of global health security [442]. In the face of this neglect and misunderstanding, coupled with the lack of existing medications and vaccines, it was unlikely that WHO officials would choose to override the bureaucratic procedures of the triaging of EIDs. Such missed alarms may be an inescapable consequence of pandemic preparedness systems that seek to rationalise responses to the emergence of new diseases [436] but do not take into account the local cultural and emotional context.

The Ebola crisis exposed inequity in global development that ultimately shaped a societal vulnerability and a lack of empowerment for communities to respond effectively [450]. Emotions became more prominent in the response to this epidemic because local communities and organisations were not empowered with education, good health, adequate income and health knowledge, so as to be better in diagnosing and responding to their own crises [450]. Thus, they were left dependent on a top-down global response, not effectively linked to local action.

Ebola was not the last new and lethal pathogen to emerge. In today's globalising world, we have a new context for infectious pandemics – larger human populations, unprecedented volume of transnational movement, rapid travel, and growing global inequalities in economics and health. What made Ebola different from the many other epidemics was the fear of contagion that the lethal disease had precipitated among the public, in both low income and rich countries. As such, it generated learning for next time that public health organisations should not wait for the rich and powerful to feel threatened in order to accordingly redirect global political priorities.

Zika in Brazil, 2016

Context

For more than 50 years, the Zika virus was believed to pose little threat, with 80% of infected individuals never showing symptoms [472]. As a result, Zika received a lack of scientific and public attention, with no efforts made to develop a vaccine or treatment, given the perceived low level of severity associated with the virus.

However, this situation soon changed after 2007, when large outbreaks of Zika Virus Disease (ZVD) were reported in Micronesia, French Polynesia and Brazil. The virus spread primarily by the *Aedes aegypti* mosquitoes, but also through sexual contact and from pregnant women to their foetuses. Most concerning, Zika was found to be associated with severe neurological disorders [473], including microcephaly in newborn babies (a rare condition in which a baby is born with an unusually small head and shows developmental delays) and Guillain-Barré syndrome (an immune disease that can cause permanent disability and even death). In response to these warnings, the WHO declared the Zika epidemic a Public Health Emergency of International Concern in February 2016.

As Zika spread to more than 60 countries, its impact was disproportionately higher for pregnant women living in low socioeconomic areas; with inaccessible (and even non-existent) healthcare and sexual and reproductive services, and unsanitary conditions that proliferated the spread of *Aedes aegypti* mosquitoes. This population experienced the worst effects of Zika and were subject to high levels of psychological distress [474]. Therefore, despite initially being perceived as having little impact, the Zika virus spread quickly, highlighting and exacerbating the inequalities that existed in the countries that it affected.

Epidemiology

The Zika virus was first discovered in 1947 in a monkey from the Zika Forest in Uganda and the first human cases of Zika were reported in 1952 [475]. Before 2007, only 14 human cases of Zika had been identified sporadically across Africa and Asia; however, as the majority of people with Zika do not show symptoms (and if they do, these symptoms echo other diseases), it is likely that many cases prior to 2007 have been going unrecognised [476].

In 2007, the first large outbreak of Zika was reported on the Yap Island in Micronesia, with 73% of the Yap residents infected [477]. Between 2010 and 2014, subsequent infectious outbreaks were identified in Cambodia, the Philippines and Thailand, and in 2013, another large outbreak occurred in French Polynesia, spreading to other islands in Oceania [475]. In 2015, Brazil experienced an outbreak of Zika; the disease was thought to have spread to Brazil during high profile international events: the 2014 FIFA World Cup tournament and the Va's World Sprint Championships, both hosted in Brazil [478].

In addition, the rapid spread of the Zika virus seemed to have been facilitated by several factors [479], including:

- (a) Tropical and sub-tropical climates forming a breeding ground for *Aedes aegypti* mosquitoes.
- (b) The deforestation and urbanisation of forest areas and ever-expanding human population.
- (c) Travel to and from affected countries on public transport, leading to Zika's widespread transmission.
- (d) Individuals' lack of any prior immunity to ZVD because it was a disease new to many regions.
- (e) The asymptomatic nature of ZVD, meaning many cases went undetected.

During the peak of the epidemic in 2016, a total of 205,578 cases were reported in Brazil, with a study in Salvador suggesting a peak seroprevalence of 63% [480], with reports of suspected microcephaly cases increasing 10-fold within just a few weeks since November 2015 [481]. An estimated 17% of women infected with the virus were pregnant, but important demographic and socioeconomic data were missing in most notification forms, impeding the targeting of measures to high risk women [481].

In November 2016, as several countries reported decreases in the number of Zika cases, the WHO announced an end to the epidemic's international emergency status and by May 2017, governments in Brazil and Colombia declared the public health emergency over [482, 483]. However, as new cases continued to be reported, some public health experts questioned if the withdrawal of the emergency status might have been issued too early and could deprioritise efforts to effectively respond to the epidemic [484]. Indeed, to this day, the long-term effects of

the virus remain poorly understood, with the experiences and needs of women and children affected by Zika seemingly ignored by governments and health authorities [485].

Society and politics

The rapid increase of ZVD cases since the end of 2015 found Brazil's public healthcare system, Sistema Único de Saúde (SUS), underfunded for a number of years. Despite an initial promise to address poverty and the social determinants of health, those commitments were not accompanied by funding basic healthcare infrastructure and workers [486], and by the mid-2010s focus had shifted away from supporting social policies towards reviving political confidence [487].

To address growing concerns around the Zika outbreak, the Ministry of Health in Brazil developed a policy strategy to respond to the epidemic that emphasised three major pillars: (i) vector control, (ii) assurance of access to healthcare for those infected, and (iii) increased investment in research and development [488]. However, the plan was criticised for not being accompanied by a clear budgetary allocation or transparent data on access to care [489], and overall the government's response to the ZVD epidemic has been considered as lacklustre and not proportionate to the real risk posed by the epidemic [487, 490].

This response was hardly unexpected, when considering the context of policy decisions and challenges that were in existence before Zika emerged. Whilst the three pillars of the policy strategy required close co-ordination and accountability, their development and delivery were fragmented and diluted, even in the face of increased pressures by the WHO for a strong policy response [487].

Given the modes of transmission, the distribution of cases and who was most vulnerable, how governments responded to the issue of protecting vulnerable pregnant women and addressing abortion rights is of particular interest in this case.

Government recommendations that women should delay childbearing during the Zika virus epidemic have been widely criticised; these warnings were not accompanied by sufficient services or information which would enable women to make informed choices about their sexual and reproductive health. Asking women to postpone pregnancy in a society dominated by Catholic and Evangelical churches, where women have limited access to contraception and abortion to start with, and are faced with high levels of sexual violence, was critiqued as

unrealistic and irresponsible [485, 491]. Instead of receiving the support and tools to navigate the Zika virus outbreak, women were often faced with stigma, violence or criminalisation when trying to access sexual and reproductive health services, where they existed at all in the first place. In the wider Latin America and Caribbean regions, it is estimated that 56% of pregnancies are unplanned [492], with most of the region only allowing abortion in cases of rape, incest or immediate risk to the mother's health. In El Salvador, abortion is illegal under all circumstances and it can carry a prison sentence of up to 50 years [493].

Even in countries where abortion was legal, many women were unable to access these services. In Brazil, some healthcare professionals would refuse to deliver contraception or abortion services as a result of their own religious beliefs, despite these services being authorised by the Ministry of Health [485]. Additionally, many women in northeast Brazil had to pay for contraception themselves because they were unaware that they could access these services for free through the public health system [485]. These findings highlight the lack of dissemination of information regarding women's sexual and reproductive health.

Moreover, it has been found that what were considered newsworthy and easy-to-depict features of the Zika virus, such as its transmission by mosquitoes and potential to cause microcephaly, were covered more extensively in the media than its sexual transmission [494]. This led to the public being less aware of the risk of transmission. Women living in areas of deprivation felt particularly uninformed by government messaging regarding ZVD. In the Center for Reproductive Rights' research, nearly half of the Brazilian women interviewed were unaware that Zika could be transmitted sexually [485]. Similarly elsewhere, in Colombia many women knew that Zika could be transferred by mosquitoes, but not that it could also be through sexual intercourse [495]. It is clear, therefore, that many women living in poverty were inadequately informed about the risks and consequences of Zika, and in the worst cases, were not given the resources to prevent the transmission of Zika to their unborn babies.

Economy

As with many other epidemics before, the spread and impact of the Zika virus was exacerbated by economic inequalities. In the poorest communities, people were living in unsanitary conditions, where untreated open sewage, standing water and irregular access to safe water enhanced the proliferation of mosquitos and subsequent spread of the Zika virus [474, 496].

Even though Latin American countries, including Brazil, have improved water access in urban centres substantially during the last decade, the underfunding of water services in more rural areas has created inequalities between urban and rural populations [497].

Additionally, prior to the epidemic, many people in regions predominately affected by Zika were unable to receive healthcare. For example, in Latin America more broadly and the Caribbean region, 30% of the population could not afford healthcare and 21% were unable to access it due to geographical barriers [498]. Brazil's SUS, underfunded, did not provide adequate financial and technical support to the regions most afflicted [487]. This contributed to poor quality of care for women and newborn babies afflicted with Zika, and, as a result, many families were not receiving adequate specialist support for their children with congenital Zika syndrome, leading some mothers to leave their jobs because of the need to care for their children. This contributed to a further exacerbation of inequality and levels of poverty [499].

Therefore, the Zika virus was often referred to as a 'disease of poverty': the lack of government investment in healthcare and sanitation infrastructures left poorer communities especially vulnerable to the detrimental effects of Zika [500]. .

Healthcare and public health

In 2016 (and indeed to date), there was no vaccine or specific treatment option available to prevent or treat Zika. Since the symptoms of the disease were mainly self-limiting (for example, fever, headache, and rash), recommended treatment involved bed rest, intake of fluids and paracetamol as a medication for fever and pain [501]. One practical preventative response that was recommended by the WHO, the Pan American Health Organization and the Centers for Disease Control and Prevention (CDC) to stop the spread of the disease was vector control, which aimed to reduce Zika transmission by limiting mosquito populations [502]. Specifically, one of the earliest responses in Brazil involved extinguishing mosquito reservoirs and advising pregnant women to wear long clothing, apply insect repellent and sleep under mosquito nets to prevent mosquito bites [503]. However, due to demand, the cost of these protective products increased, preventing many women (especially those of low socioeconomic status) from purchasing them [485, 504].

As part of vector control, in January 2016, the National Biosafety Committee in Brazil approved the release of genetically modified male *Aedes aegypti* mosquitoes throughout the country

[505]; when mating with female mosquitoes, these genetically modified mosquitoes transmit a gene that causes their offspring to die, thus reducing the population of *Aedes* transmitting Zika. After releasing the genetically modified mosquitoes in a test region in Brazil, the *Aedes* populations were reduced by an impressive 90% [506], therefore offering a safe and effective method of preventing Zika. However, this measure was not without criticism from environmental groups, who were concerned that releasing a novel mosquito strain and eliminating an entire mosquito species might affect the populations of other species and damage the ecosystem over time [507].

An additional group of public health responses to Zika were related to sexual and reproductive health; following evidence that Zika could be sexually transmitted, women were advised by the CDC to abstain from unprotected sexual intercourse with male partners who had lived in or travelled to Zika-affected regions [508]. Additionally, public health officials in Brazil (as well as in Colombia, Ecuador, El Salvador, Jamaica and Puerto Rico) recommended that women postponed pregnancy (for two years in the case of El Salvador) [474]. In response, the Office of the High Commissioner of Human Rights [OHCHR] and other women's rights organisations advocated for increased access to abortion and family planning services [491]. The Colombian government adhered to this advice, allowing all women infected with Zika the opportunity to abort [509], but no other Latin American country followed their example.

The suspected link between Zika virus infection and microcephaly was a highly debated topic in academia and practice. Controversies included the sensitivity and specificity of the cranial measures to define microcephaly and variable causes of microcephaly. It is likely that the need to get consensus about this public health crisis impaired subsequent investigations and the debates and controversies resulted in delayed responses, especially for the women and girls suffering the worst impacts of the Zika epidemic [481]. These were added to the inadequate healthcare provision as outlined previously.

Culture

Since the Zika virus primarily affected pregnant women, it created a high level of fear and psychological distress amongst this population group. The media was found to intensify, rather than ease, fear and panic; pregnant women reported feeling especially afraid about Zika due to reports in the media that the virus could lead to birth defects, including brain damage [510]. As

with other epidemics (for example Ebola), media messages were often alarming, repeatedly using the actual words for emotions such as “*fear*”, “*panic*”, “*anxiety*” and “*worry*” [511]. In one news article, a medical specialist, Dr Schaffner, described Zika as “*enormously anxiety-provoking*” [512]. News coverage often included misleading headlines, labelling Zika as “*spreading explosively*” with “*four million possible victims*”, and used visual imagery, including pictures of mosquitos (Figure 4.12) or babies with microcephaly, to shock readers [474]. Unsurprisingly, these alarming news messages further amplified fear and concern amongst the public.



Figure 4.12. Reprinted from *The History of Zika*, by Credit: Chato Stewart, MentalHealthHumor.com, 2016.

In Brazil, mass media used a communication framework of drawing a war against the virus. An analysis of the coverage of the epidemic in two major newspapers, showed that they adopted this *war frame* focused on a war against mosquitoes and viruses as a health, epidemiological and scientific issue [513]. People were presented with apocalyptic scenarios with Brazil needing to put an end to the *Aedes* mosquito to avoid the mosquito putting an end to Brazil [514]. A second war frame was focused on a war against microcephaly with women being the main target audience. By focusing on women’s personal responsibility and placing the burden of responsibility for prevention on them, Brazilian media failed to capture the nuance and regional distribution of gender and social inequalities in the country [513].

A result of unfavourable policies and gender inequality, mothers of children with microcephaly (now based on newspaper coverage visually rapidly assessed by a smaller head circumference) reported feeling ostracised by others in their communities who feared catching the disease from the children [515]. This stigma was persistent and linked to the lack of health education and scientifically sound articles available to the public, leaving many people to rely on alarmist and misleading media coverage as their source of information regarding Zika-related microcephaly [474].

Emotions around the Zika epidemic in the literature

The Zika epidemic with its uncertain scope and dramatic clinical outcomes for newborn babies caused an environment of fear and psychological distress, predominantly for women, but also for the wider public. Even though it was the fifth most studied infectious disease in my systematic review, only three studies, attempting a total of four correlations, were identified assessing whether public emotional responses led to the uptake of public health interventions. A recent study has focused on the role of hope and trust amongst healthcare workers [134].

All studies were published in 2018 and were of high quality. Two larger studies from Germany and the US assessing the emotion of fear as a motivator for action with a cross-sectional survey design, found that it had a negative effect on the uptake of public health interventions [215, 217]. A cohort survey of women in the US found that fear was counterproductive to their preventative behaviour against the pandemic and, in fact, none of the psychological mechanisms employed by the participants worked to down-regulate their fear [217].

A high quality study conducted in Puerto Rico identified clear underestimations of the health risks associated with the Zika virus linked to a general indifference for many participants. Those who expressed feeling of worry and concern, on the other hand, were more likely to follow recommended personal preventative strategies [214].

Discussion – The emotional determinants of the response to the Zika epidemic

The Zika epidemic exposed and exacerbated the inequalities and stigmatisation that persisted in Brazil (and more broadly in Latin America and the Caribbean). The Zika virus was described as a “*disease of poverty*” because it brought about disproportionately worse outcomes for those in

economically disadvantaged communities, where unsanitary conditions and inaccessibility to protective measures, like mosquito repellent, contributed to the proliferation of the *Aedes aegypti* mosquitos [500]. Therefore, to minimise the deleterious effects of such outbreaks, interventions needed to target individuals' relative risk to the virus; for example, responses to Zika should have focused on strategies that minimised the catalysts of poverty, such as access to clean water, sanitation and appropriate housing [516].

Not only did Zika expose the economic inequalities that many communities were facing, but the epidemic was a reminder of women's lack of rights and access to sexual and reproductive health services in many Latin American countries. Prior to the epidemic, women were not provided with the resources to make informed decisions about their reproductive health; yet, despite this, governments continued to advise women to delay pregnancy during the epidemic. This governmental approach was deemed irresponsible and neglecting of the lived experience and rights of women who were trying to navigate the health risks of ZVD [485]. It was stipulated that following the experience with Zika in 2016, women should be transparently informed of the sexual transmission of Zika, its prevention and consequences, and provided with unbiased information and access to sexual and reproductive health services [516].

In some places, like in the Southern areas of the US, where the *Aedes aegypti* mosquitos were present and posed a threat of transmitting Zika to the population, the majority of women (aged 18-35) were reported being afraid, with those who were or planning to be pregnant reporting the highest levels of fear [217, 510].

Zika's detrimental impact on mothers of children with congenital Zika syndrome highlighted the lack of support available for these families. Alarmist media messages regarding Zika-related microcephaly amplified fear and concern amongst the public; rather than increasing people's self-protective behaviour, this fear-based messaging contributed to the ostracism of mothers of children with Zika-related microcephaly due to misunderstandings around the spread of the virus [515]. In addition to providing the public with quality information during health crises, public health campaigns on Zika should have shifted their focus away from fearmongering and towards messages of hope and support which empower people to effectively navigate and overcome the epidemic [517]. However, public health messaging alone is not enough to enable individuals to overcome the impacts of an epidemic; for example, psychological support should be provided to pregnant women who have been affected by Zika virus infection, so that they can prepare for childbirth and be supported post-pregnancy [474].

The Zika epidemic created fear and psychological distress not only for pregnant women, but for mothers of children with congenital Zika syndrome. Twenty-four hours after giving birth, Brazilian mothers who had newborn babies with Zika-related microcephaly were found to report higher levels of anxiety and lower psychological wellbeing than those with healthy newborn babies [518]. Over the following year, the mothers' anxiety increased, with their quality of life remaining low [519], illustrating the long-lasting impacts Zika can have for many women and their families. Importantly, in this research [518, 519], the mothers were from impoverished, rural areas in Brazil and received no psychosocial support or counselling after giving birth to their children with microcephaly. Additionally, many partners were found to abandon women after their children had been diagnosed with Zika-related abnormalities [474]. It seems unsurprising, therefore, that women were reporting such high levels of psychological distress in response to Zika [519]; with no support from public health officials or their partners, many impoverished mothers were left with no means to care for themselves or their children. For many women, this context created a vicious circle of mistrust of authorities and guidance due to fear, poverty, distress, poor outcomes, and exacerbated fear.

Several public health experts criticised the prioritisation of vector control methods to prevent the spread of the virus because it resulted in the abandonment of alternative systemic strategies, including improved water and sanitation infrastructure, and the provision of comprehensive sexual and reproductive health services [485]. It is evident, therefore, that human rights were not at the core of response efforts to contain the virus, despite the marked role that economic and gender inequalities played in driving the epidemic and exacerbating its impact [474]. A human rights-based approach is critical to adopt when addressing health crises, such as the Zika outbreak and, as outlined by the Center for Reproductive Rights [485], requires:

- (a) Access to scientifically sound and comprehensive information about the virus, its risks and prevention.
- (b) Access to inclusive sexual and reproductive health services, including contraception, abortion and counselling services.
- (c) The provision of adequate standards of living, including access to sufficient, safe and physically accessible and affordable water.
- (d) The provision of welfare plans that enable the inclusion and development of children with disabilities.

Overall, the Zika outbreak highlighted and amplified the inequalities that existed in the countries that it impacted. Governmental agencies and healthcare providers failed to prioritise the populations that were most vulnerable to the effects of the virus, let alone address their expected emotional responses by attempting to productively engage, inform and empower them to take prophylactic action. The Zika virus epidemic in Brazil vividly showed that when overcoming current and future health crises, it is vital that response measures are developed with human rights and equality at the core; without which, the spread of the virus will be fuelled, and its health and social impacts worsened. Ignoring those may further exacerbate unpleasant public emotional responses and impact on the uptake of interventions.

DISCUSSION

“Leadership is not about necessarily being the loudest in the room, but instead being the bridge, or the thing that is missing in the discussion and trying to build a consensus from there.”

(Jacinda Ardern)

Quoted in NewsHub Online, May, 2019

5. DISCUSSION

In marketing, fundraising, humanitarian crises, and corporate crises, emotions are understood and accepted as a core part of crisis communications. My thesis contributes to the growing evidence that emotions have an important role to play in driving protective behaviours and the uptake of interventions, especially in times of public health crises. People experience diverse emotions at a time of a crisis and these have the capacity to influence their interpretation of it and guide their behaviour [520]. This principle should be no different in public health crises.

Research on emotions from a risk science perspective has shown that initial cognitive processing of a situation gives rise to emotions, which in turn guide the further, more elaborate, cognitive processing which is driving behaviours [521]. This framing helps move the conversation away from views of emotions being irrational and a debate of whether reason or emotion is more dominant in the functioning of the human mind. Humans are capable of complex behaviours, and emotions have the capacity to change people's perceptions, attention, and memory by guiding them to focus on aspects of their environment that they'd consider important [522].

Epidemics and pandemics can trigger certain emotions, or their lack, which can in turn lead to outcomes with their own emotional consequences [119]. By combining evidence from a systematic review and five in depth case studies, my thesis shows that emotions are shaped by wider influences and have the capacity to impact population responses. Several common themes can be extracted from these different sources of evidence to guide thinking and recommendations on emotional determinants.

Common themes

Fear- and panic- based public health campaigns do not work or have non sustainable impact

The evocation of fear through emotive language and graphic imagery has been used extensively in public health campaigns. Public health professionals and policy-makers have historically drawn attention to, and prepared for, emerging infectious diseases by raising the spectre of catastrophe, generating fears that the media and politicians are often willing to amplify [523]. Within the public health community, as well as within marketing, advertising and other sectors,

there is still a commonly held view that fear- and panic-based campaigns are effective in changing behaviours through creating anxiety in those receiving a fearful message [524, 525]. This attitude has been perpetuated by a false belief that this approach can increase awareness and funding [523].

An expanding body of research has been produced on this issue, some of which firmly support that fear-based campaigns are an effective way of increasing people's self-protective behaviour [526]. Even though fear-based messaging has since been found in several studies to result in non-sustainable, and often undesirable outcomes including stigma and mistrust towards authorities [260], many still support this earlier view of effectiveness [525, 527]. Whilst this view is still endorsed by some, discussions around the use of fear in public health messaging have mostly focused on the bioethics of the issue, on the basis that several fear-driven appeals have been linked to stigmatisation of vulnerable populations [525, 528].

In my thesis, I argue that – at least in the case of epidemics and pandemics – public health campaigns that appeal to fear are not effective in motivating protective behaviours in the public. The evidence looks clear, both from my systematic review and through almost all the national case studies, be it because of responses to political fearmongering or reactions to fearful and emotive imagery in the media. Fear-based campaigns sow the seeds of panic, stigmatise people associated with the disease, and compromise an evidence-based response that would be most effective [523].

This is consistent with evidence that has shown that appeals to fear used to promote care where there is no good supporting evidence are fallacious and ineffective [524] and with management literature that has shown that, at times of organisational crisis, the stronger the unpleasant emotions, the less likely employees are to report behavioural intentions that are supportive of an organisation [529]. This knowledge could be readily applied to emerging infectious diseases as, by definition, they are emerging as new threats in a context of limited specific evidence. Fear related behaviours are often triggered in response to either perceived threats or actual exposure to a potentially traumatising event [132].

In my study, fear is not to be confused with anxiety, which was a strong positive predictor for uptake of interventions. This is consistent with psychological research based on appraisal theory which suggests that fear and anxiety are distinct constructs and fear is far less influential than anxiety in motivating seeking and paying attention to protection-related information [130].

When fear-based messaging is becoming even more extreme leading to responses of panic, responses becomes even more counterproductive and I could not identify a single study or qualitative evidence suggesting that evoking panic leads the public to more informed health behaviours. Comparative studies of periods of “*germ panic*”, though, have shown that the experience of triggering of public panic across a period of 100 years has remained remarkably similar. There are long-term cultural trends that contributed to the making of obsessions with germs and they reflect anxieties about societal incorporation, associated with expanding markets, transportation networks, and mass immigration. They were also shaped by new trends in public health education, journalism, advertising and entertainment media [530, 523, 531].

Further, it is counterproductive that popular media and policy makers persist in strategising on the assumption that panic is a common – even typical – response to crises and disasters [131]. Psychological research has shown that resilience, cooperation and normal social conduct are often maintained at critical moments [41]. Panic, then, has often been prompted, not by infectious disease threats per se, but by the social, political and economic forces that these threats were associated with or exposed [131]. Popular media, cultural influences (e.g. movies) and populist political communications have been essential for panic to have become a phenomenon beyond the individual and the local [532].

Lastly, from an ethical point of view, the use of fear and panic through emotive messaging and imagery in public health communications is often impacting even more significantly on minority or high risk communities. In the case of AIDS in Australia, the Grim Reaper advertisement seemed to be successful among the general population, but failed to motivate gay men to action [148]. In the case of SARS, the evidence was clear that people (predominantly from Asian minority communities) who were feared and stigmatised, delayed seeking care and often remained in the community undetected. This led public health professionals to call the fear, stigmatisation and discrimination in and of minority communities as the epidemic within the SARS epidemic [533].

The power dynamics of ‘top-down’ communications need to be disrupted

My study shows that part of the reason why certain public health campaigns fail to deliver to evoke the right emotions that lead to the desired outcomes is down to the role that governments and public health and communications experts (the producers of information) play

compared to the public (the receivers of information). Due to a combination of “emergency thinking” mindset and the existing distribution of power in different areas, the usual way to communicate in an emergency has clearly been the traditional and unhelpful “top-down” approach (that is, “experts” or the state imposing messaging on broad populations) [534, 535]

The case studies presented suggest that the episodic and uncertain features of epidemics give control measures a pronounced tactical character. The general public is seen as passive and, in most cases, vulnerable to the infectious disease. Communication focuses on promoting public compliance with prescribed guidelines, at best without inspiring complacency, panic or other unruly responses [536].

These approaches, however, are derived from assumptions and a limited social imaginary of the public response to epidemics. They rely on a restricted view of human agency and therefore preclude alternatives to compliance-complacency-panic and, in fact, as my study shows, compromise pandemic control. On this basis, it has been argued that effective pandemic control requires a systematic dialogue with the public it seeks to prepare in anticipation of the event of the epidemic crisis [536].

Behavioural research, especially studies in psychology and risk, has shown that despite the fact that both experts and the public share certain biases, they often have genuine conflicts of values. For example, in the case of infectious outbreaks, a key driver for public health experts is to prevent significant mortality from the infection. These fatality rates are almost always counted as number of lives or number of life-years lost to a disease. Members of the public, though, often draw distinctions between “bad” and “good” deaths. These can be defined in terms of accidents or “fate”, younger or older people, otherwise healthy or people with long-term conditions, and so on. Whilst these distinctions are clearly emotional, they are unavoidable and legitimate. In fact, they show that whilst public health experts have a good grasp of overall risk based on statistics, this often ignores the richer conception of risks that members of the public have [537, 37]. A quantitative approach on its own, cannot account for this difference in values. In my study, the use of case studies aimed to help bridge this gap.

To help address these issues, public health professionals and government should be resisting the view that experts should rule and that their opinions should be accepted without question when they conflict with the opinions and emotions of other citizens. Each side must respect the insights and intelligence of the other [37, 537]. However, to achieve this, the policies and models

being pushed by those in power need to be disrupted, and the most effective way we have to do this in a crisis setting is through co-production [538, 539].

In simple terms, co-production is about developing more equal partnerships between people who use services, carers and professionals [540]. In practice, its aim most often is to bring greater involvement for groups that are more representative of community needs and more opportunities for local capacity building and empowerment [541]. In line with how epidemic public health communications sometimes lead to marginalisation, co-production approaches have been linked to the provision of more inclusive, equitable and responsive health and public health services [542], and to more effective and inclusive hearing and promotion of views of marginalised groups [543].

However, evidence from sustainable development research has warned that such efforts to empower and learn from previously disadvantaged or non-consulted groups cannot exist within a political and social vacuum [544]. The ways power has been structured and distributed due to historical circumstances, influences the power dynamics between those planning the public health communications as “experts”, the immediate stakeholders who distribute them as “players” who hold power, and the public who is receiving information traditionally with relatively little influence. It is very difficult for co-productive methods to overcome or mitigate entrenched, unbalanced power relationships, and the outputs of such efforts have remained biased towards the agendas of those more powerful [545]. Hence, it is down to public health professionals and the state – as those holding the power in these circumstances - to disrupt what is allowed on the agenda and produce health literacy messaging in collaboration with communities (and in a way that addresses their concerns and emotions) and stop treating the public as passive recipients or – potential – victims who do not understand their own problems [546].

Post-colonialism and other abusive histories should be acknowledged and new trust-building initiatives designed between global and local actors

My research has yet again exposed a well-recorded problem in global health: a postcolonial legacy through which the global North holds much of the power in international decision making and the global South is not represented across all areas of global health.

This is reflected in the findings of my systematic review. Whereas a range of unpleasant and pleasant emotions was assessed in studies from European and North American nations, when it came to studies in Africa, only extreme unpleasant emotions (such as fear and panic) had been studied and used in public health communications. In addition, there were no studies from Central and South America identified at all.

Global health as we interpret it today through research, programmes and policy is the evolved configuration of what used to be tropical and colonial medicine. Most major institutions, however, are still practicing and teaching global health in a way that is depoliticised and ahistorical, without a clear acknowledgement of the oppressive roots of global health, such as colonialism, slavery, and racism. These are often hidden by a focus on universal interventions and communications [547, 548].

As shown in my research, this has important implications on the emotional determinants of health in two ways: (i) in the building of trust through public health communications when epidemics appear as “foreign threats”, and (ii) in the collaboration between states and the ability of higher income countries to expect or impose measures, resource allocation and even language to low and middle income countries.

First, for example, in the face of HIV risk in the late 1980s, black communities in the US and elsewhere feared that AIDS might be a form of genocide targeted at minority populations [549]. Similarly, an outbreak of cholera in Haiti in 2010 was received in four Haitian communities as a disease deliberately spread for political reasons by foreign agencies or national authorities [550, 551]. A similar emotional response was yet again repeated in the mid-2010s in West Africa where outbreak control teams were sometimes feared as they were seen as spreading the Ebola virus as part of a political genocide campaign [552]. Such fears of national and international authorities are born long before a crisis and are more nuanced than usual conspiracy theories as they are, more often than not, a result of historical top-down and inappropriate public health and political approaches [553, 551]. They underlie the value of contextualising global responses down to a supralocal level, and the main way to meaningfully and effectively address them is through psychosocial interventions that include participatory discussions, facilitation of community acceptance, conflict mediation, all within a context of thorough understanding of the local cultural drivers of people’s emotional responses.

Second, in several of my case studies (especially in relation to nations in crisis, such as in West Africa, Greece and Brazil), the notion of foreign powers expecting and imposing measures was

clear. Highly deadly and contagious infections, such as Ebola and in some cases Influenza, are examples of epidemics that need to be seen as having the capacity to potentially escalate into a global health crisis. To contain cross-border spread, international collaboration, policy harmonisation and institutional adaptations are required. These include intergovernmental coordination, intervention from international organisations, as well as synchronisation of state efforts with subnational responses at a regional level. Cross-sectoral involvement is needed as well, from, among others, civil society, non-governmental organisations, commercial airlines, and pharmaceutical companies [554]. To achieve this, calm, organised and evidence-based communication across political borders and sections is essential. For it to meaningfully address emotional determinants, the globalisation of infectious disease agents as well as the globalisation of the science and biomedicine that are used to address them, need to be viewed critically through a postcolonial lens [555].

The role of media at times of epidemics needs to be reconsidered

Either through broadcasting public health recommendations, fearmongering through sensationalist stories, or critiquing governments' managements of epidemics, my study has shown the clear role that media have in shaping the public's emotional responses at times of crises. In turn, media coverage has been shown to be influenced by the social, economic and commercial circumstances in each nation.

News media have an important part to play in informing the public. However, they have been criticised for aggravating the impact of infectious disease outbreaks by intensifying fears and increasing risk perceptions, predominantly through the overly emotion-laden nature of news reporting, sensationalist news and use of emotionally arousing individual cases [556, 557, 558]. Most research on media in the context of health crises has focused on the effects of emotion evoking in relation to risk perception and affect, but not on perceptions of vulnerability and behavioural intentions [559]. Whilst more recent research has been trying to address this gap [556], the role of media in COVID-19 has remained controversial [560].

The challenge of news media playing a positive role is further aggravated by the timings and momentum of their coverage. For example, media attention for influenza A H1N1 in Europe declined long before the epidemic reached its peak, and public risk perceptions and behaviours seemed to have followed media logic, rather than epidemiological logic [561]. Further, in an

ecological study of 23 European countries on avian influenza, it was shown that each additional hour of average television viewing was independently and significantly associated with a 15.6% increase in the proportion of people worrying about a pandemic caused by H5N1 virus [562]. With fear of a pandemic preceding a real pandemic, public emotions need to be addressed separately depending on their cause and target.

Naturally, the way that people consume information in the modern world has gone through rapid change. The media cannot be seen simplistically anymore as agents of social control especially since people had always had their own, historically constructed, views of epidemics and infectious diseases [563]. The key question in relation to emotional determinants is how media messages interact with public perceptions and preconceptions, rather than how the former structure the latter. However, my case studies show that the media had a significant role in the element and the social construction of the different epidemics as public issues.

For example, media coverage of AIDS in Australia in the 1980s and 1990s evolved as the perception of the condition moved from the “gay plague” to the “innocent victims” narrative [158, 254]. Coverage started from the initial stages of inciting homophobia and a moral panic, moved to the unprecedented (and largely un-followed) intensification and dramatisation through the Grim Reaper campaign, and then went to a plurality of subjects many of which focused on different elements of risk and vulnerability [256]. In achieving an evolving coverage of the AIDS pandemic, Australia had the benefit of forewarning and a stable progressive government [564]. This cannot be (and has not been) the case with other epidemics that emerge with little warning in countries with unstable political systems. Rumouring, fear provoking coverage, and use for political purposes has been noted in the cases of the SARS and H1N1 outbreaks [328, 565].

With the influence of traditional print and digital media dramatically decreasing in favour of social media, the emergence and expansion of “fake news” [566], along with the evidence that public emotional responses are socially constructed and people consume media increasingly with a focus on assessing risk [556], a reconsideration of the role of media in epidemics is urgently needed. As shown in my study and has been supported previously by risk science research, emotion evocation and dramatisation in the news media occur within a pre-existing complex interaction of, among others, social, political and commercial factors [567]. Past normative assumptions about “ideal journalism” that objectively quantifies actual risk for its audience [567] are not that relevant anymore. As risk perceptions are socially mediated and

emotional responses socially constructed, the coverage of epidemic crises in the media should go beyond the objective risk, and rather include the power struggles that are happening behind the scenes between the several claims makers (experts, governments, public) who seek to impose their preferred vision of the risk [568]. Long gone should be the days of using “strategic ambiguity” in public service and commercial announcements that perpetuate stereotypes and ignore nuanced differences in the population [569]. If media are to remain relevant and useful during crises, transparency, open debates, honesty about journalists’ own emotions, and informed critique should become the norm.

To meaningfully appeal to emotions, public trust building is necessary well before an outbreak

National investments to facilitate prompt access to safe and effective healthcare measures and non-pharmaceutical interventions have little merit if people are not willing to follow a recommended measure during an emergency or inadvertently misuse or miss out on a recommended measure. The public's topics of concern, emotional requirements, capacity for processing information, and health needs are evolving as an emergency unfolds, from a pre-event period of routine conditions, to a crisis state, to a post-event period of reflection. Thus, as clearly visible across the different evidence sources in my thesis, communication by public health authorities requires a phased approach that spans from building up a reputation as a trusted steward of health measures between crises, to being an honest communicator during the crisis, and to developing recovery-focused messages about applying newly acquired data about safety, efficacy, and accessibility to improve future situations [570]. Trust in health information is critical to responding to health crises, as exchange of information and cooperation is intensified within networks of trust [571]. Following the evidence of my systematic review that specific emotions have the capacity to serve as determinants of health behaviours, how trustworthy authorities, scientists and big business are perceived as by the public can be a key mediator in what emotions official communications evoke, and, hence, a key influence on the behaviours of the public.

It is well-known that disease tends to flourish during times of economic crisis and social chaos. Economic crises result in high rates of inflation, unemployment, widespread poverty etc. These reduce the standards of living conditions, disrupt access to healthcare, lead to risky behaviours and impact on mental health. Further, during such times, malnutrition increases, lowering

resistance to disease [572]. This is a perfect storm making it extremely challenging to build trust during a crisis. Trust needs to be built over time so that it becomes the underpinning social framework in which health interventions can thrive, and hence health outcomes can improve [31]. In a systematic review, greater trust in authorities was associated with protective behaviours during a pandemic [413].

This all means that trust should be built long before the time that it matters most. For example, in the case of the 2009 H1N1 pandemic, the public wanted to be reassured that there is enough vaccine, but certain groups were questioning the safety and effectiveness of the vaccine [31]. In China in 2003, a perceived lack of government transparency, at least in the initial phase of SARS, recalled earlier public health incidents and episodes of public dissension, notably the Tiananmen Square protests of 1989 [573], whilst at the same time in Singapore, the key ingredient in their successful containment of SARS, was transparency and reassurance in public communications that were followed by tangible actions; all built through achieving trust domestically despite implementing strict measures [574]. Pandemics are crises, and times of crisis are times of uncertainty that rarely lead to mature decisions. Instead, they lead to emotional decisions. Therefore, even though trust is imperative in a crisis, public suspicion of governments and experts are also increasing during a crisis due to several reasons, including access to more sources of conflicting information (especially through social media) and to exposure to scientific uncertainty and party political debates [575].

Trust is by definition highly relevant to emotional determinants, and is, in many ways, the basis of co-operation. Perhaps confusingly for authorities, trust had been defined as the confident expectation of the benign intentions of others [576], whereas it would be more complete to describe trust as the confidence that someone's action will correspond with one's expectations (either benign or not) of them [577]. Not unsurprisingly then, in my case studies, trust was consistently a mediator of the public's emotional responses heavily impacting their uptake of public health interventions. As emotional contagion has the capacity to erode the public's trust in such interventions [107], experts and authorities should move towards a mode of communicating that is underpinned by trust building and factors in the evidence identified in this study, including co-production, transparency, resilience, vulnerability, and external influences. These will be important in the sense of learning and taking into account what the public is thinking, saying, feeling and acting on [578].

In this context, if a government or authority has not managed to build trust prior to the emergence of a crisis, they should consider making use of external influences on trust. These are non-medical sources of information that might be better trusted for health advice [571]. At times of immense polarisation or in countries with divisive political leaders, it is highly likely that the distrust in the purveyors of public health messaging could evoke unpleasant and/or counterproductive emotions – regardless of the content of the messaging – that will not help increase uptake of interventions. This is further compounded by the fact that liberal and conservative voters are driven by different emotional forces and sensitivities and disagree on many moral issues [579]. In such politically divided contexts, authorities should move beyond politically partisan divides and collaborate with leaders from non-medical communities (e.g. faith leaders, employers, teachers) to share consistent and transparent communications.

There is a place for more listening and empathy in public health communications

The outcomes of evoking pleasant emotions, such as empathy, hope and compassion, remain little researched and understood in public health. My study adds some evidence to this issue. The emotion of empathy, in particular, emerged as a key motivator for action in my systematic review, being positively and significantly associated with uptake of public health interventions, primarily personal prophylactic measures and following recommended measures.

This has predominantly been studied in the context of coping. A reasonable hypothesis is that when individuals are able to cope with the stress and fear of a high risk infectious disease through focusing their concern on the needs of others, they would be more likely to engage with public health measures that are recommended and not engage with behaviours likely to be socially damaging [180]. This is consistent with the research on prosocial behaviours, in which empathy has been well documented as leading to more effective social functioning that is of benefit to both the direct recipients of actions and behaviours and the wider society [580, 581].

Consequently, an empathetic and open style of communication has been found to be the most effective when officials are attempting to galvanise the population to take a positive action or refrain from a harmful act during a crisis. Empathy and caring show honesty, dedication and openness, all of which are essential elements in persuasive communications [575]. For example, in a study of pregnant women during the H1N1 pandemic, some participants identified a contradiction between the culture of caution which characterises pregnancy-related advice, and

the fact that they were being urged to accept what was perceived as a relatively untested vaccine [582]. Making decisions on the basis of the “*lesser of two evils*”, or “*the slightly better one choice*” is a heavily emotionally charged process, and open communications rooted in care and compassion could help address these contradictions and mediate more protective decision-making by the public.

Consistent with this, an empathic response to the threat of SARS was found to predict increased engagement in recommended health precautions, independent of the level of perceived viral threat [172]. This finding was replicated in a study of response to West Nile virus [180], and a study in the H1N1 pandemic setting during which the pandemic vaccine was produced and distributed [208]. These findings suggest that empathic responding may be modifying the effect of the stressor itself to facilitate protective health behaviours [208, 172]. Public health communications, then, need to be urgently refined to incorporate and acknowledge the important role that empathy can play.

Other pleasant emotions, such as hope and compassion have not been studied in depth, though there is emerging research. In both cases, their possible capacity to be motivators for action may lie in which contexts they are used and how their protective potential can be harnessed.

Maintaining hope for people in high risk groups that may be marginalised and disadvantaged can have a positive protective effect linked to preventative behaviours. For example, in an early 1990s qualitative study of women at high risk of AIDS in the US it was found that women practiced safe sex because of hope, but did not believe it would be effective [157]. In the theory of positive psychology, hope is seen as goal-directed thinking; characterised by the combination of the ability to find routes that lead to desired goals with the motivation needed to reach those routes [133]. This could lend itself nicely as a mechanism for hope to lead to increased uptake of interventions in public health.

Given the capacity that inherently exists in compassionate responses to produce better health outcomes [583], providing good quality transparent information to communities that practice compassion may help harness that as a cultural trait, instead of a behaviour that might create increased chances of touching and transmitting a virus, as happened during the Ebola outbreak in West Africa.

How the evidence from this study relates to the COVID-19 pandemic

Since late 2019 and to the point of finalising this thesis, the world has been facing the COVID-19 pandemic. Over the past few months, the pandemic has grown to be seen as a “*once in a century*” event and pandemic because of some fairly unique characteristics: efficient transmission, considerable fatality risk compared to other pandemics (though lower than the 1918 flu pandemic), and an unprecedented set of measures globally which meant that at some point in April 2020 as much as one third of the world’s entire population was under lockdown measures at the same time [584].

The pandemic, either directly through personal or family experienced morbidity and mortality, or indirectly through the immense media coverage and the endless political debates, has generated, fuelled, and amplified a wide range of emotional responses [119]. Evidence seems to be emerging around emotions that is largely consistent with what my thesis has identified in other settings, and certain experts and national leaders have appealed to public emotions in a variety of successful or unsuccessful ways [119, 585, 586].

Similarly to my thesis, such emotional responses need to be clearly differentiated from any mental health related symptoms or other psychiatric responses. For example, in my thesis, feeling an anxiety, stress, worry or concern in relation to an epidemic was important in motivating following public health recommendations. When it comes to health anxiety (hypervigilance to potential illness), though, it has been associated with various maladaptive behaviours which, even when consistent with public health recommendations, can be taken to an extreme that may have negative consequences to the individuals or their communities [587]. Similarly, viewing oneself as at low risk of illness may also make it unlikely to change their social behaviours and lead to failure to adhere to recommendations [588]. I expect more evidence on this issue to be published in the context of the COVID-19 pandemic response.

While most of this evidence is yet to be peer reviewed or systematically synthesised, my thesis is providing a useful framework and recommendations that are relevant to responding to this pandemic. The COVID-19 measures have exposed what has also been clearly shown through my case studies: that a holistic approach to the management of infectious disease outbreaks is required. It ought to be one that addresses the social implications of strategies that are drawn from medical knowledge alone, as an epidemic impinges on the social and emotional lives of people and how they interact with each other under stressful circumstances [589]. Social and behavioural science, as well as co-productive, methods need to be used in the ongoing

negotiations with the public as nations globally are navigating their course through the pandemic [586].

Without such a holistic understanding of people’s emotional and behavioural responses, the pandemic exposed, in several settings around the world, policy decision-making based on “folk psychologies”, including ineffective assumptions that the public will necessarily panic and be incapable of taking the responsibility needed, as well as counterproductive emergency management strategies based on coercion and withholding information from the public [590].

The COVID-19 pandemic has one further core difference to the previous outbreaks studied in my thesis which is that it has emerged in a world highly interconnected through social media. Even though social media platforms were in existence in the Ebola, H1N1 and Zika outbreaks, their growth in the past five years has been even more exponential and their role in the emotional responses to infectious disease outbreaks needs to be considered carefully. The way in which information has been consumed, perpetuated and manufactured, via social media, during the COVID-19 pandemic is certainly unprecedented [591], and represents a big difference compared to the previous epidemics studied in my thesis.

Epidemics in a world connected through social media

Within weeks of the emergence of the novel COVID-19 disease in China, misleading rumours and conspiracy theories had started circulating the world, often mixed with fearmongering messages, racist narratives and mass purchases of face masks, toilet rolls and other goods. These have been closely linked to the ecosystems of the 21st century largely hosted by social media, and a panic through social media has been travelling faster than the spread of the virus [592].

This has not been unexpected. Social media platforms have created new social networks and relationships and are allowing the spread of rumours, research, support, and misinformation at unprecedented rates [593]. Crucially, they have also created new and alternative opportunities of trust building through peer-to-peer interaction [594]. As previously mentioned, this is vital to take into account when considering how certain emotions can be evoked depending on who the source of information is. This is a global phenomenon beyond health. In business management, for example, it used to be taken for granted that the voice of the Chief Executive Officer (CEO) carries more authority than low grade employees [595]. However, a survey conducted in 2018 by Edelman public relations group found that only 47% of employees trusted the CEO for advice

and 44% the corporate board for advice. In contrast, 61% and 53% trusted "*a person like me*" and a "*regular employee*" respectively [596]. Research like this has introduced the notions of "*horizontal trust*" which is rising faster than "*vertical trust*" and it has considerable implications for the role of social media during an epidemic.

In other settings, this has been harnessed in both positive and negative ways. For example, the #MeToo movement through social media enabled once fragmented voices to unite at speed [597]. Cyber crowd protests have been erupting over social and environmental issues, driving an explosion in shared values-based activism, most recently over the #BlackLivesMatter movement. However, at the same time, when it comes to science and truth denialism [598], this new digital world has fed conspiracy theories and protests that snowball so quickly and unpredictably that it is hard to fight back.

Peer-to-peer communication and the emergence of horizontal trust in cyber space is contributing to a shift in the patterns of trust towards a world of "*distributed trust*", where more faith is being placed in the wisdom of online networked crowds than people running institutions [599]. By providing easy access to conflicting information and self-proclaimed experts, social media platforms serve to undermine trust to the right experts [575]. "*Fake news*" and tribal politics, amplified by social media, are further contributing to distrust [600].

Social media can and should be harnessed for good in public health [592]. Targeted social media can combat misinformation. For example, in the case of Human Papilloma Virus (HPV) vaccination, Denmark faced groups alleging through social media and television news that young girls had been harmed by the HPV vaccine which led to very significant drops in national immunisation rates. In response, Danish public health officials emphasised the risk of disease, and promoted empathetic stories on social media of people who had lost wives and mothers to cervical cancer. They also created a Facebook page for answering parents' questions. Following these, the numbers of people vaccinated started increasing significantly again [107].

It is important to keep in mind how digital media forms differ in terms of the journalistic standards they adhere to. While the public often expects professional journalists to be detached and unemotional reporters, they hold no such expectations towards users of social media. Consequently, people evaluate the presence of dramatic characteristics, such as emotive language or tragic stories, differently depending on whether they appear in traditional or user-generated media forms. Additionally, social media audiences tend to be more segmented, reaching only certain sub-populations, for instance special interest groups and established "echo

chambers”. Therefore, emotive stories have different effects depending on how broad or narrow, universal or specific, audience they are reaching [398].

Beyond an immediate understanding of the cyber space though, the experience of previous epidemics and pandemics has shown that it is the local context and attitudes that drive emotional reactions and influence the cultural responses to risks. These responses, in turn, impact how public health addresses epidemics and how the collective memory of a crisis is shaped. The interaction of this local context with the digital world is important to take into account as government and public health agencies are planning measures and communications.

The steady stream of information and the “24-hour news cycle” that are available today via social media, make it particularly hard to navigate the complex information environment, especially in times of crises. As the example of COVID-19 has vividly shown, the information flowing through these digital channels is often not filtered for accuracy, or not put into the proper context for the recipients so they can act on it properly. As a result, there’s the very real danger that people may miss critical facts to guide their decision-making, or may take specific actions based on misinformation, which can ultimately lead to unwanted outcomes. This puts the onus even more on health professionals and elected officials to be proactive in designing effective risk communication strategies [601].

Recommendations for practice and focusing future research

Some clear recommendations for practice and research are emerging through the evidence in my thesis.

In public health practice

- Consider emotions in crisis communications and work with trusted leaders

Crisis communication is defined as the collection, processing, and dissemination of information required to address a crisis situation [602]. In this thesis, I have presented epidemics and pandemics as crises. Emotions are clearly influenced by crisis communications from authorities and are clearly playing a role in influencing behaviours. Public health should draw from evidence from psychology, organisational management and elsewhere which has shown that emotions are one of the anchors in the publics’ interpretation of crisis situations [603, 604]. Meaningfully

speaking to the public's emotions at times of polarisation may also require delegating the purveying of health information to trusted non-medical and/or non-government leaders.

- Communicate risk clearly

Maintaining trust throughout an outbreak investigation requires transparency (that is, communication which is candid, easily understood, complete and factual) [605]. According to risk communication principles, messages need to be simple, easy to understand, tailored to community diversity, and responsive to peoples' emotions within the situation [601, 606]. This is not a new concept and should extend to also communicating the uncertainties around risk clearly as well (especially in the early stages of epidemics). AIDS researchers and practitioners have been pointing out since the late 1980s that clearly articulated public education and, in particular a willingness to correct misinformation, can contribute significantly to overall prevention efforts by easing fear and enhancing the climate in which people at higher risk of HIV infection can receive and respond to targeted messages [607].

- Co-produce communications and measures

Working with people and communities as partners in the design of services and communications brings benefits not only in terms of more positive acceptance of messages from authorities, but also increased trust in public health measures. A literature review has found that patient and public co-production in health can have a number of benefits but uncertainty persists about how to do involvement well and evaluate its impact, and how to involve and support a diversity of individuals to genuinely allow for the influencing of decision-making [608]. This they conclude can leave co-production open to criticisms of exclusivity and tokenism. Current models of co-production are often too narrow to one area of health and few public health agencies mention empowerment or address equality and diversity in their crisis communications strategies, often because of an emergency/urgency thinking mindset. Co-production can include: (i) co-design (including planning of interventions), (ii) co-decision making (in the allocation of resources), (iii) co-delivery of interventions (including through community volunteers), (iv) co-evaluation (of the service) [609]. The adoption of models and frameworks that enable power and decision-making to be shared more equitably with the public in designing, planning and co-producing public health interventions can be what makes the difference in a crisis setting and it should be prioritised in exactly the same way that convening groups of experts by background is prioritised.

In public health research

- Define emotions clearly and use in conjunction with beliefs

My study has shown that beliefs, alone, do not predict public behaviours. The Health Belief Model (HBM) model suggests that an individual will decide to engage in a given behaviour aimed at preventing or treating a disease based upon their beliefs about the perceived threat of the disease and beliefs about the benefits and risks of the target behaviour. Two reviews in the past decade examined predictors of H1N1 vaccination intention and action and found, consistent with the HBM model, that beliefs about the perceived threat of the disease and the benefits and risks of being vaccinated were important predictors [610, 94]. However, all studies reported focused on specific beliefs related to the H1N1 virus, and ignored individual differences in general beliefs and characteristics that may influence the decision making process, such as the ability to tolerate uncertainty, general fears of contamination, coping styles, and current emotional state of the participants. Building on that, a study on H1N1 from Germany found that the cognitive estimation of a risk was no longer a significant predictor when the feeling of risk was also used to predict the willingness to be vaccinated with the pandemic vaccine [611]. Future research should incorporate both cognitive and affective aspects of risk estimation when it comes to individual's willingness to follow recommended public health interventions. In addition, when emotions are studied they need to be clearly defined and differentiated from each other.

- Study emotions with new frameworks

In an investigation of the 2002–2003 SARS epidemic, a study proposed a model in which the threat of infectious disease is conceptualised as a stressor [172]. Accordingly, relevant behaviours such as handwashing and vaccination may be best understood by examining individuals' coping responses to this looming threat, reflecting previous models of coping with disease [612]. New research frameworks will be needed to produce a more nuanced understanding of how emotional responses are born and influence during health crises. This is particularly relevant to empathic responding and prosocial responses to distress that may predict distinct forms of behavioural responses to the threat of global viral infections. Research indicates that coping strategies are associated with engaging in health behaviours in response to health threats. Future research should expand on how ways of coping are investigated, and

should attempt to investigate the potential effectiveness of promoting effective coping and decreasing maladaptive strategies in response to future health threats [180].

More sophisticated and targeted research and evaluation analyses are also needed when it comes to understanding which outbreak responses are most effective. Comparative psychobehavioural surveillance and analysis could yield important insights into generic versus population-specific issues that could be used to inform, design, and evaluate public health infection control policy measures [170]. The Appraisal Tendency Framework, which proposes a theoretical connection that links one's discrete emotions with their cognitive appraisals, could be used more in public health [5]. Researchers should use the opportunity of real world infectious disease outbreaks – such as the current COVID-19 pandemic – to study emotional regulation in natural settings, that is, what strategies individuals use to manage their emotions in the face of risk [217].

- Use different study methods

While much important data about epidemics as crises can be gathered by questionnaires, surveys, literature reviews and case studies, the actual processes by which people and communities respond to risk, threat, vulnerability, impact, and recovery are best understood through on-site ethnographic research [11]. Despite taking a holistic approach into analysing a range of existing data and sources of information, my thesis has not followed such methodology. It is well known that methods that privilege narrative and observation, with researchers present and in dialogue with participants to gather local knowledge and information, are far more appropriate for exploring the process of preparation and adjustment – and, hence, the emotional determinants at play – than more synchronic forms of research [613]. Future research should strive to identify areas of high risk based on the social context and lead ethnographic methods to better define the determinants, their interactions and their potential in improving preparedness and uptake of interventions at a local level.

Strengths and limitations

For my work – which carries in many ways the principles of global history – to be meaningful in 2020, I had to ensure that any production of knowledge at a global level is not ignoring decades of progress in scholarship by turning away from analyses of power in history or of the local perspectives. Rather, such histories should critique globalisation and postcolonialism as sets of

institutions, discourses and practices [614]. Despite being a single researcher from an institution of the global North, I hope to have achieved this through my critical use of national case studies and an interdisciplinary discussion of common themes.

Nevertheless, despite taking an interdisciplinary approach, I have not been able to use existing evidence to draw clear quantitative and qualitative conclusions. The limitations of my literature review are detailed in the relevant section of the third chapter. The literature on emotions in public health is far from systematic and the use of frameworks and definitions not shared across different methods.

Secondary sources have primarily been used throughout my thesis to support the wider context or as the basis for further research. These have been complemented by contemporary primary sources (as well as press and media materials), especially to inform the national case studies. The advantages of using contemporary press materials, where these were available in the form of newspapers and magazines, for historical research are obvious. They are readily available, their reports are close to the events narrated and are the work of people directly involved or of witnesses of the events described [615]. In fact, despite their limitations, newspapers can often constitute the only available source of information [616]. However, not only does the press share all the weaknesses of human testimony in general, but it also has a few other inherent limitations. Journalists' occasional efforts to get the news out as quickly as possible often militated against the accuracy and reliability of their reports. Moreover, publishers and editors frequently let their personal biases influence the decision of what to print and what not [615]; it is this selectivity that heavily questions the validity of newspaper information. They are incredibly useful, however, in capturing the emotional context of each era.

Through studying epidemics as they emerged in different settings, I have used several resources from eras when the infections were not entirely scientifically understood. That is why the primary focus of this thesis has not been epidemiological, rather to provide a social and contextual point of view on emotional determinants. As with any study delving into a little researched topic, further research will be needed to more clearly define these determinants and to explain causal routes to behaviour change. I have outlined research recommendations to help towards achieving that.

CONCLUSION

“Somewhere out there a dangerous virus is boiling up in the bloodstream of a bird, bat, monkey, or pig, preparing to jump to a human being”

(Dr Jonathan D. Quick)

Quoted in “The End of Epidemics”, by Jonathan D. Quick, with Bronwyn Fryer; Scribe: Brunswick-London, 2018.

6. CONCLUSION

The history of epidemics and pandemics is closely intertwined with our emotional responses to them. AIDS was the “*gay plague*” that generated anxiety morphing into panic and paranoia. SARS brought waves of public frenzy and cross-border discrimination. H1N1 felt overwhelming when it started and unimportant after a few months. Ebola drew an “*ecology of fear*” around it. Zika influenced a continuum of anxiety, inequality, despair and hope.

My thesis brings some clear evidence on the influential role of emotional responses to the risk of infectious disease outbreaks. Such is their influence that talking about emotional determinants, when it comes to public responses and uptake of public health interventions, is an entirely reasonable language to use. Epidemics make headlines, capture the public’s imagination, and ignite their fears in ways that other acute or chronic illnesses do not [410]. As the COVID-19 pandemic is making its way through different nations, and then through to our emotional memories, much of the emotional response of the global North seems pre-defined and similar to the past: the emergence of H1N1 was about a virus that “*was novel and mysterious; it emerged from a teeming third-world city, and it was now making its insidious – and seemingly unstoppable – way toward the “civilized” world*” [617]. Such narratives need to be disrupted if we are to use the evidence on emotional determinants and show a willingness to learn and alter our collective consciousness in ways that will be productive and save lives during the COVID-19 pandemic and when future epidemics emerge.

My thesis has also shown that emotional determinants, like epidemics, are not born in a vacuum. Eminently social, epidemics are worked out in complex interactions and discourses in which the needs and interests of many involved individuals, groups, and organisations are articulated and negotiated over the often extended duration of the entire phenomenon, including the period leading up to the epidemic emergence [11]. This pattern is similar to the development of emotions – and emotional responses – in individuals and populations.

Epidemics and pandemics are the ultimate emergency tests to global health, and in being so they have, in a sense, been diseases of society. They hit the underprivileged due to living conditions, threaten many countries simultaneously, test the efficiency of local structures, prompt novel public health measures [618]. Thus, a history of epidemics and pandemics should above all be a social history of crises and confidence and certainly something more than a study

in historical epidemiology. In my thesis, I have tried to balance the evidence on the interactions between global and local contexts.

Similarly to ethical and philosophical research conducted on specific epidemics, understanding outbreaks and emotions as an interactive relationship requires to unpack and illuminate practices, stories and histories, unequal distributions of power, knowledge and resources and the consolidation of inequalities through institutions. In addition, it requires a comprehension of the narratives between “Us and Them” and North and South, between the past and the present, between the lived experiences of those directly or indirectly affected by outbreaks, and between the diverse ways of knowing and understanding the world [619].

In the model of health transitions, as nations develop, they go through predictable epidemiologic transformations. We need to contextualise epidemics through social science approaches which include the grounding of case histories and local epidemics in the larger biosocial systems in which they take shape [68]. The case studies in my thesis show how connected we are as a global community. In many ways, when it comes to epidemics, we are only as safe as the most fragile states.

In addition, it is unlikely that any policy for the implementation or distribution of public health interventions will be able to succeed until public fears that motivate counterproductive behaviours are addressed [620], and the interplay between perception, emotion and behaviour in the public is understood well by governments and public health agencies and professionals. To achieve this understanding, public health professionals should question the overreliance on thinking that beliefs are predominantly and solely governing decision making when it comes to health behaviours and open education up to emotional determinants. In addition, more work is needed at both global and national levels to ensure that populations can acknowledge and own their emotional responses, and are empowered to protect themselves from diseases, and to ensure that the mass media have the knowledge and understanding to contribute to health protection and understanding of risks and their management [464].

The call to action in my thesis is certainly not new. In fact, some 30 years ago, in responding to the spread of AIDS, many professionals proposed building on the experiences of past programmes to slow the spread of the infection, counter the prevalent panic and fears, and utilise available therapeutic and public health resources [621]. The emergence of this behavioural approach to understanding responses to infections has its origins even earlier, and

was popularised – among the scientific community – a lot more in the 1960s through ethnographic work on intravenous drug use [622].

To be successful this time in 2020, public health needs to move away from purist approaches and start employing modern methods. Public health scientists often carry an obsession with integrity and a deep belief that evidence will speak for itself. This is a hindrance. In public health, we need to become adept at using tools that others regularly do, but that may make us uncomfortable, including repeating emotionally appealing catchphrases. If we understand the value of emotional determinants, applying tools that others use, such as appropriately emotive language, personal stories, sound bites, and marketing could be surprisingly effective, especially if done well and for the right reasons for the greater public good [35].

The reality of the COVID-19 pandemic and the learning from the outbreaks of the past 30 years, shows that government and public health communities need to urgently invest in incorporating the role of the emotional determinants – in the context of the wider social determinants – to ensure that they can break the cycle of “panic-neglect-panic-neglect”, in which nations fail to prepare adequately and then respond to an outbreak with ineffective and needlessly draconian measures [623, 98].

In doing so, we have to bring back long-termism and historical perspective and not just short-term thinking, and use cross-disciplinarity in understanding and responding to infectious disease outbreaks as complex biopsychosocial phenomena.

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INTEGRATING STATEMENT

8. INTEGRATING STATEMENT

With a background in medical studies and a Doctor of Medicine (MD) degree qualification from the University of Athens, a choice of a non-clinical career is a certainly an unconventional one in my native Greece. Since graduation, I have been trying to expand my education and shape a career in public health, which I am now looking forward to underpin with the Doctor of Public Health (DrPH) degree qualification.

In 2013, having recently undertaken a Masters degree in Medical Humanities (with a focus on the History of Science, Medicine and Technology) shared between Imperial College London and University College London, I got accepted at the DrPH programme at the London School of Hygiene & Tropical Medicine. I deferred my admission for a year as I had recently taken up a new public health research and development role in the Medicines & Healthcare Products Regulatory Agency (MHRA) and I was better exploring the field and work.

I started my degree in September 2014 on a part-time basis whilst working full-time, a pattern which I continued for the whole six years of the degree, with a change in employer four-and-a-half years ago. I see my experience of the past few years and all the components of the DrPH degree as critical in helping me keep growing in a public health career.

DrPH Taught Component

The course started with two compulsory face-to-face modules: (1) Understanding Leadership, Management and Organisation, and (2) Evidence Based Public Health Policy and Practice.

Those two courses provided a wealth of resources and food for thought, allowed me to dive into the theory and application of public health, and through assignments and presentations helped me refine my understanding of the discipline and the ways it is practiced in different parts of the world.

Of particular value was the interaction with my fellow students, all emerging leaders in their fields, coming from many different countries around the world. The course maximised peer to peer learning through discussions, presentations and debates in class, and a two-day residential programme we all took together in the first year focusing on personal leadership development was fundamental in honing my understanding of leadership skills and learning from others in a safe and relaxed space. I have been readily applying this knowledge to my work since.

Organisational and Policy Analysis (OPA) Project

With my interest growing in public health leaderships and communications, on the back of the taught courses, I undertook an Organisational and Policy Analysis (OPA) project through my place of work then at the MHRA, at a different department. This focused on customer service in public health and included reviewing existing customer service policies in the MHRA and comparing those to culture and practice. In my submitted work, I formulated recommendations towards supporting improved customer service functions and consistency across the MHRA as a key function enabling delivery of its public health mission.

I submitted my assignment, entitled “*Customer service from policy to practice: insight from a UK Department of Health agency*”, concluding that providing high quality public health information to an increasingly broad spectrum of stakeholders required a successful combination of factors, including efficient use of technology, acceptable levels of staff knowledge of customer issues, and an appropriate business culture.

Skills gained in the taught component, such as conducting strategic analyses and understanding how diverse public health organisations operate, were incredibly valuable in completing a successful OPA project and assignment.

My immersion in this topic and work not only helped me apply the theoretical knowledge from the taught component into a practical issue related to an organisation, but further build my understanding of organisational management in public health terms. Supported by my growing knowledge and confidence in this space I first secured a promotion within the MHRA, and subsequently moved, on promotion, to the Mental Health Foundation, a UK-wide public mental health charity with a particular focus on communications, research and policy, where I’ve been based since and during my thesis.

Thesis

In conducting my thesis, I have tried to bring together the various skills I’ve gained throughout my studies and career so far, and in particular those I gained from the DrPH programme. Fundamentally, my thesis is looking to enhance how we, as public health professionals, can communicate more effectively with the public at times of public health crises, and how we can motivate action and uptake of interventions.

This topic and approach:

- Have been inspired by my fundamental interests during my medical studies, in terms of how more people can be enabled to live healthier lives, and how knowledge from local and national settings can be applied globally;
- Have been supported by my Masters studies which gave me critical research skills in historical research and analysis (as well as, crucially, the value of contextualising knowledge to a certain time place) which I used for a big part of my thesis;
- Have been enabled by the taught courses which helped me expand my literature review skills, especially when it comes to reviewing the evidence with an intention of producing applied knowledge that should be accessible and readily available;
- Have been further supported by my experience in the OPA which clearly helped me, in a very practical sense, understand the value of engaging core stakeholders in a way that is appropriate to each audience;
- Have, lastly, been honed and applied through my work at my current workplace, where public health communications are a fundamental part of what we do as an organisation.

I have been passionate about addressing and reducing the impact of epidemics and pandemics for many years. I have a particular interest in better understanding risk and inequality in the context of public health, as well as responding to risk, and achieving effective communication of risk. My in depth study of risk in the context of public health crises for my thesis has helped me connect many dots from my many years of diverse training together, in terms of linking those topics to the fundamental issues of the social determinants of health and real world evidence.

Concluding thoughts

As I'm writing this Statement, the COVID-19 pandemic is still a major issue around the world with millions at risk and economies struggling. Whilst on one hand, I do personally feel that I have achieved all of the objectives that I had when I was applying to this programme, I cannot, on the other hand, help but think that, in many ways, my journey is only just starting.

In the past few weeks of doing the final checks and revisions of my thesis, my brother fell ill with COVID-19. His underlying health risks (obesity, diabetes, depression, history of cancer) meant that he soon became a difficult case, admitted to a university hospital specialist infection unit with pneumonia and had a difficult and stressful treatment course. He is still fighting the disease as he is one of the complex cases. Experiencing his illness first hand, I have not been drawn back to my clinical background, nor have I been advocating for more investment in treatments and medications, important as they may be.

The devastating experience of my brother's illness – as for millions around the world – makes me even more convinced that public health solutions hold the answer:

- Better prevention of obesity and diabetes through addressing the commercial determinants of health.
- Better prevention of depression through addressing inequalities.
- Better prevention of cancer through addressing the social determinants of health.
- Better prevention of serious infections through more effective public health communications that can inspire and motivate people to take protective action.

I will continue to try to make an impact on the above as well as on the response to COVID-19, in my academic and professional capacity, as well as a member of Public Health England's COVID-19 Mental Health and Psychosocial Support Reference Cell, and a newly invited member of UK Government's Scientific Pandemic Influenza Group on Behaviours (SPI-B). With the holistic experience and knowledge I gained through this DrPH course I am ready for the rest of my career dedicated to public health. I believe in co-produced innovation, real world research and fair policies. And in relentlessly trying to influence better health & better lives for all, under any circumstances.