The Anticipative Medicalization of Life

Governing Future Risk and Uncertainty in (Global) Health

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Governing future risk and uncertainty in (global) health[1]

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The unforeseeability of potentially fatal risks and threats to our health are a fundamental characteristic of the human condition. Because of the fragility and finitude of life, our future bodily integrity seems particularly precious. The desire to foreknow and control the coming is therefore perhaps never as existential and immediate as when it comes to questions of health and illness. Drawing on recent works on risk and uncertainty in biomedical anthropology, this chapter seeks to demonstrate how at the beginning of the twenty-first century the future has become an ever more important reference point in the world of health. While individual and global public health differ in the exact methods they apply to control future illnesses, in both realms we witness today a trend towards the 'anticipative medicalization' of life, to borrow Foucault's term: the creation of an 'increasingly dense and important network' of big data-driven diagnostic and surveillance technologies that allows fewer and fewer potential risks to our well-being – diseases, pathogens, defective genes – to escape (Foucault 2003: 273).

In the first section of this chapter, I will use the example of (pre- or post-natal) genetic testing and diagnosis to exemplify how individual health is more than ever shaped by attempts to predict and prevent the onset of illnesses. While this opens up new avenues for preventive healthcare, the societal implications cannot yet be fully estimated. Arguably, the 'predictive euphoria' of certainty and controllability could also be leading towards a risk avoidance imperative in the future. Individuals might be pressured to be aware of, control and manage their genetic inheritance far-sightedly and to make the 'right' (reproductive and lifestyle) decisions in light of potential genetic risks. In more general terms, this can be interpreted as a move from primarily curative and remedial measures towards prediction, manageability and prevention.

A similar anticipative turn is observable on the global level, even though the applied technologies are different. In the second (and central) section of this chapter I will show how today's global efforts at communicable disease mitigation likewise mirror attempts to foresee future public health threats through the collection and analysis of large amounts of health-related data. However, since the prediction of outbreaks and pathways of communicable disease risks is still in an early stage, global health policy needs to employ different tools: A recently established, dense net of all-risk surveillance structures for the real-time detection

of (newly) emerging disease events is supplemented by measures to achieve preparedness and resilience.

Despite the different methods at play on the individual and the global levels, there appears to be a larger, unifying pattern: I argue that we can observe a growing desire to anticipate and reign over our future health by expanding the range, functionality and applicability of biotechnological tools and practices of prediction and surveillance based on big data, digitalization and artificial intelligence.

Predictive genetic diagnostics, actual risk assessments and the individualization of responsibility

In May 2013, Hollywood actress Angelina Jolie publicly disclosed in a *New York Times* article that she had undergone prophylactic breast cancer surgery after finding out that she carried a mutation of the so-called 'breast cancer gene' BRCA1 – a rare genetic condition that significantly increases the risk for developing certain cancer types among women (Jolie 2013; Kamenova *et al*. 2014). While her public revelation and the ensuing media coverage were certainly unusual and in large part due to her particular status as a global celebrity, her choice is emblematic for a larger trend in (Western, industrialized states') human medicine. Since the start of the Human Genome Project in 1990, scientists have been making ground-breaking advances in the field of human genetics. These developments have made it possible not only to sequence and catalogue the 3 billion human DNA base pairs, but also to search for gene–disease associations, i.e. for gene mutations that might cause illnesses even at later stages of one's life. Facilitated by the fast growth of digital healthcare, artificial intelligence and machine learning, genetic epidemiology and molecular diagnostics and, subsequently, the preventive treatment of potential medical conditions have become major and fast growing pillars of modern medicine. The National Center for Biotechnology Information, for example, now lists more than 10,000 medical conditions for which genetic tests are available (NCBI 2018).

Although critics caution against flawed and over-deterministic interpretations of today's diagnostic results (Katsanis and Katsanis 2013: 423) and point at the many unsolved questions surrounding the security and ownership of personal health data, the novel tools of genetic testing and engineering have heralded the dawn of a new societal perception of individuals' susceptibility to health risks and of people's risks of falling ill, be it at birth or in adult life. Individuals are thus no longer allocated to specific risk groups according to epidemiological criteria such as blood pressure, exposure to environmental pollution or the like. Rather, a person's individual genetic code is deciphered, presumably allowing for the calculation of assertedly precise personal risk-levels. The impact of this new industry of (pre- and post-natal) predictive techniques is not limited to immediate questions of intervention and therapy. It ultimately opens up avenues for genetic engineering, enhancement and selection. Many philosophers and medical ethicists have long warned that this

'purificationist imperative' (Elshtain 2005: 170) might not only lead to an individualization of health risks, but also pave the way to genetic discrimination and stigmatization, if not human enhancement or eugenic selection of offspring (Habermas 2002; Sandel 2007).

This 'predictive euphoria' of certainty and controllability engenders expectations regarding individuals' 'appropriate' behaviour and their 'right' reactions towards these risks (Feuerstein and Kollek 2001). Because tests of genetic susceptibility and the identification of genetic 'deficiencies' are now widely available in many middle- and high-income countries, individuals become impelled to preventively find out their genetic health risks and manage their bodies and reproductive choices accordingly (Akabayashi 2014; Rose 2001: 19). The 'good genetic citizen' is obliged to control and govern his or her genetic set-up carefully and far-sightedly, to make the right (reproductive) decisions in light of predicted risks and to change his or her behaviour accordingly (Braun 2007: 12). However, if not regulated properly, 'the results of a genetic test might make some people practically uninsurable. The ensuing financial and human burden for those individuals might be equitable from a commercial standard but is still unacceptable from a societal perspective' (Nill *et al*. 2017: 3).

Despite these concerns, there seems to be a widely shared belief and trust in the benefits of genetic predictive techniques and genetic (self-)management. Arguably, Angelina Jolie's decision is thus not merely an individual-personal decision, but reflective of a broader, societally anchored socio-technical imaginary of preventive health managerialism or, as I call it, 'anticipative medicalization':[2] It is emblematic of an incremental expansion of medical practices and techniques in order to govern future health threats (Clarke *et al*. 2003; Conrad 2008; for a critical review of 'medicalization', see Davis 2006; Foucault 2003; Nye 2003).[3]

The trend towards the actuarial assessment and prediction of risks and towards individual, preventive risk-reduction and controllability of future life trajectories on a personal medical level is paralleled by a similar rise of 'anticipative medicalization' on the global level. As I will illustrate in the next section, we can observe that in recent decades the discourse in global health has shifted from a notion of defence against concrete, known illnesses towards a fear of uncertainty and uncontrollability of pathogens. This gave rise to a substantial reform, expansion and deepening of global health governance and big data-driven biomedical surveillance. This assemblage is complemented by efforts in preparedness and resilience (or what Collier and Lakoff (2015) call 'vital systems security'), since the emergence and spread of new diseases still remain unpredictable to a significant degree.

Global health governance in perspective: fighting communicable diseases

International efforts against the spread of diseases are not a new phenomenon. Early measures can be traced back to the quarantine regulations established to protect Venice and other seaport cities from plague in the fourteenth century.

Due to, at the time, insufficient insights into infectiology and disease causation, these regulations were grounded in a rather vague knowledge of pathogenic dangers. This changed, when in the early nineteenth century governments began to systematically collect statistical data on their populations (including dates of birth and death, cause of death, marriage status, profession, place of residence etc.), thereby laying the foundation of modern epidemiology (Hacking 1990). The gathered data allowed for a better understanding not only of risk factors, but also facilitated the retrospective observation of regularities and patterns such as the burden of diseases, incidence rates and mortality levels across a population and its sub-populations or in particular geographic areas. The International Sanitary Convention of 1851 reflects this rise of modern epidemiology and medical sciences and marks the first coordinated multilateral effort in evidence-based disease control (Davies *et al*. 2015).

It was only through the establishment of the World Health Organization (WHO) in 1948, though, that a more harmonized and comprehensive set of regulations replaced the hitherto patchy and weak provisions. Two principles became central for the organization's work against communicable diseases: (1) States have a duty to inform each other about the occurrence and outbreak of specific diseases on their territory; and (2) they are obliged to limit disease-countermeasures (border controls, quarantine, import bans etc.) to levels that do not unduly harm international trade and travel (Fidler 2005: 328). For most of the twentieth century, however, the regime actually only dealt with the threat posed by a very small number of known contagious diseases. The proactive control of illnesses was restricted to the fight against cholera, plague, yellow fever, smallpox, typhus and relapsing fever (World Health Assembly 1951: Art. 1; see also Fidler 2005). However, WHO had to rely on reports by governments and had no enforcement capability in case of non-reporting or undue protective measures. As a result, delayed and asynchronous or even non-reporting was widespread, since states were afraid of the reputational or economic drawbacks of transparency (Davies *et al*. 2015: 5). Moreover, any infectious disease or pathogen that was *not* part of the WHO list would not be governed by the classical WHO regime and states had no obligation to report such outbreaks.

Public health progress towards the eradication of certain syndromes (e.g. smallpox) and more general advancements in medicine in the global North in the 1960s and early 1970s further contributed to a diminished importance of WHO's efforts at countering infectious diseases. With regard to influenza, for example, MacInnes *et al*. (2014: 49) write:

> The demonstrated efficacy of influenza vaccines encouraged the notion that governments could effectively manage the disease by themselves, a perception actively encouraged and promoted by the WHO […]. The arrival of antiviral medications in the 1960s added to the pharmacological arsenal and further embedded the belief that government-led initiatives could manage the public health problem of influenza without the need for strong international intervention.

In this phase of 'epidemiologic transition' (Tulchinsky and Varavikova 2009: 44) many of the 'classical' infectious disease were disappearing or at least becoming manageable through the means available in the industrialized world.

As a consequence, and after several adjustments, WHO's list of threatening diseases was further condensed: By 1995, it encompassed only three reportable conditions (cholera, plague and yellow fever) that were deemed to pose a risk to global public health. Going beyond a mere technical or regulative alteration, this change represented a conceptual shift in experts' perception of the future of global health: The need to collectively manage imminent disease threats was overridden by a newly arising belief in the curative medical and technological capabilities of industrialized states' healthcare capacities. The perceived necessity to prepare against communicable diseases had largely given way to a 'spirit of optimism' (Mayer 2000: 938; see also Caduff 2014: 111) and an enthusiastic faith in the controllability, treatability and curability of illnesses.

The end of optimism and the 'emergence' of emerging diseases

The optimism did not last long. It was not least the spread of HIV/AIDS and the appearance or identification of other previously unknown (or disregarded) pathogens in the 1980s that suddenly put infectious diseases back on the radar screen and radically shifted key actors' approach towards governing health insecurity (King 2004). Noticeably, the dynamic was not primarily driven by WHO as the designated international authority in the realm of global health, but predominantly by the US Institute of Medicine (IoM), the US Center for Disease Control (CDC), and a small number of key virologists and microbiologists, who assumed the prerogative to foresee the future. Acting as 'agenda-setters' and 'policy entrepreneurs' (Keck and Sikkink 1998; Mintrom and Vergari 1996), these experts warned against 'complacency' in the fight against 'bacterial, viral, protozoal, helminthic, and fungal invaders' (Lederberg *et al*. 1992: 16).

> As the human immunodeficiency virus (HIV) disease pandemic surely should have taught us, in the context of infectious diseases, there is nowhere in the world from which we are remote and no one from whom we are disconnected. Consequently, some infectious diseases that now affect people in other parts of the world represent potential threats to the United States because of global interdependence, modern transportation, trade, and changing social and cultural patterns.
>
> (Lederberg *et al*. 1992: v)

It was this report that provided a coherent, highly authoritative and novel narrative of a future shaped by emerging infectious diseases (EID) (Lakoff 2015).

The report advocated and promoted a particular concept of emerging infectious diseases, which has since gained hold in the scientific medical discourse. It distinguishes between two categories: those previously unknown pathogens that

are discovered and recognized in humans for the first time (newly emerging); and those that are known to have infected humans before but appear today in different locations or as a new (potentially drug-resistant) strain or reemerge after apparent elimination (Heymann and West 2014; Morens and Fauci 2013). Since the conditions and circumstances under which pathogens develop and transform are highly complex, 'the emergence of novel pandemic agents often seems to be inherently unpredictable', while the frequency of new emergences is increasing, Morse *et al*. (2012: 2) warn (see also Holmes *et al*. 2018). As a result, predicting a major disease outbreak is still in an early stage – despite the enormous progress that has been made in big data analytics, digitalization and AI (artificial intelligence) in recent years (Flahault *et al*. 2017; Vayena *et al*. 2018) – because it depends on the interaction of a large number of complex factors at the animal–human interface (Morse 2012; Morse *et al*. 2012; Neumann and Kawaoka 2019). Reflecting this uncertainty, the generic concept of emergence emphasizes 'potentiality': The disease 'can pass over or not pass over into actuality' (Weir and Mykhalovskiy 2010: 40).

In the following years, two disease outbreaks added further urgency to these warnings: First, the 1995 Ebola outbreak in Kikwit (then Zaire) created a globally mediated fear (at times marked by racist undertones) of deadly pathogens lying dormant in the 'impenetrable jungle' of 'backward' countries (King 2004, 2015). Second, in 2002/03, the SARS pandemic seemed to prove the EID-concept: Within just a few weeks, a severe respiratory disease spread along heavily frequented flight routes from Hong Kong to Singapore, Toronto and Vietnam, rapidly affecting more than 8,000 people across five continents: A patient from China's Guangdong province had travelled to Hong Kong for a wedding, where he infected other guests, who in turn transmitted the infection as they continued on their journeys. Epidemiological investigations later showed that wild-game animal markets in Southern China might have provided 'the interface which facilitated the maintenance and amplification of SARS-CoV precursor viruses, allowing repeated exposure of the human population and leading to inter-species transmission events' (Hilgenfeld and Peiris 2013: 288).

The popularization of the EID concept was further enabled and facilitated by broader societal and political developments: The new awareness of emerging diseases coincided with a heightened concern about bioterrorism and biological warfare that evolved (mainly in the US, Japan and Europe) in the 1990s and, even more pronouncedly, after the terrorist attacks of September 2001, conflating medicine and national security under the rubric of biosecurity (Cooper 2008: 74–81; Falkenrath *et al*. 1998). Furthermore, the reconceptualization and broadening of the concept of 'security' both in scholarly and military circles in the 1990s facilitated an integration of a wider set of (military and non-military) issues into states' security agendas (Krause and Williams 1997). This 'securitization' of health contributed to a framing of pandemics and infectious diseases as potentially existential threats – which cannot be solved by routine measures of global public health, but need a 'decisive', forceful and exceptional (yet permanent) reaction (Aldis 2008; Elbe 2010). And lastly, the fear from intangible

pathogens spreading globally and uncontrollably in an interconnected, seemingly borderless world resonated well with new notions of 'risks of modernity' that became popular in the early 1990s (Beck 1986): According to this view, growing and intensifying processes of globalization and connectivity in trade and travel not only spur the global spread of pathogens and diseases, but also reduce the advance warning time for state actors to protect their citizens, leaving them potentially unguarded and unprepared against newly emerging health threats.

The topic also blurred the lines between sober scientific analysis and fictional dramatization: Horrifying scenarios of a hitherto unknown and unimaginable pathogenic menace to humanity made their way into mass media, bestselling books and Hollywood movies (cf. Aaltola 2012; King 2002, 2004; Wald 2008). Several (both science and fiction) authors predicted the breakdown of functioning economic, political and societal structures should a deadly pandemic of 'superbugs' and 'killer microbes' emerge (Garrett 1995; Preston 1995). Others hypothesized that an

> epidemic disease may function as a stressor variable to compromise the prosperity, the legitimacy, the structural cohesion, and in certain cases the security of sovereign states. Further, diseases may exacerbate pre-existing domestic conflicts between ethnicities, and/or classes and may generate intra-societal and intra-state violence, and the resulting societal discord may generate punitive and draconian responses by the state against its people as it seeks to maintain order.
>
> (Price-Smith 2009: 3–4)

In a similar vein, WHO declared pandemic influenza 'the most feared security threat' (quoted in Enemark 2009: 191). And the so-called Spanish Flu of 1918, which might have killed up to 50 million people worldwide according to some accounts, became commonly referenced as scary evidence of the apocalyptic potential of such viruses (Garrett 2005). Together, these interpretations and prophecies contributed to a new perception of the pathogenic dangers surrounding 'us' and paved the way for the acceptance and sedimentation of the 'emerging infectious disease' worldview in academia and beyond.[4]

Later CDC and IoM reports repeated the depiction of the threat and pushed for a global leadership role of the CDC as well as US research institutes and pharmaceutical companies. King claims that the CDC aspired to be 'the source of the technology, standards and expertise, creating the computer models and risk-analysis software, furnishing regional laboratories with "state of the art" diagnostics, and training foreign personnel', in order to be able to shape the global health order (King 2002: 775; see also Weir and Mykhalovskiy 2010: 29–40). Indeed, the notion of emerging diseases put forward by the CDC soon acquired authority and political traction. It provided a central scientific impulse for an overhaul of WHO's tasks and procedures in the case of a communicable disease outbreak and of global health governance more generally.

The following paragraphs will show that this resulted in structural and organizational adjustments, which were accompanied by an epistemological shift: Based on an altered socio-technical imaginary of life in an unknown 'pathogenic future', WHO's traditional task of repelling and containing a few specific, defined health threats was replaced by a precautionary approach for anticipating and governing uncertainty. This development was facilitated by the massive rise of digital health technologies and artificial intelligence that allows for the generation, collection and analysis of huge amounts of – both structured and unstructured – health data on a global level.

Reforming global health governance: from risk to uncertainty

Initiated in 1995, the WHO reform process came to a conclusion in 2005 with the adoption of the new International Health Regulations (IHR 2005: WHO 2005b). The most important aspect of the reform process pertains to the scope of the regulations. Unlike earlier guidelines, the IHR 2005 do not merely contain a list of identified, reportable diseases, but introduce the notion of 'disease event': States are no longer obliged only to report a small number of specific diseases, but also to install on their territory a comprehensive surveillance system, a 'vigilance apparatus' (Weir and Mykhalovskiy 2010) capable of immediately detecting all those public health 'events' that have the potential to spread beyond local areas. 'Each State Party shall notify WHO […] of all events which may constitute a public health emergency of international concern within its territory' (WHO 2005a: Art. 6.1). A reportable 'event' is no longer solely defined on the basis of specific, identifiable pathogens (and diagnosed illnesses), but based on syndromes and scale ('is the impact serious?'), thereby making the scope of the application much broader and more flexible.

In order to detect all relevant events, all member states are obliged to implement a state-wide system ('functioning throughout their territories', i.e. at national, intermediate and community level) to monitor, detect and react to a potential 'Public Health Emergency of International Concern' (PHEIC). As stipulated in the new regulations, 'each state party shall develop, strengthen and maintain […] the capacity to detect, assess, notify and report events' (WHO 2005a: Art 5.1).

This entails that states institutionalize at a local or primary public health response level a comprehensive and permanent surveillance infrastructure in order to be able to collect the following event-related information: 'clinical descriptions, laboratory results, sources and type of risk, numbers of human cases and deaths, conditions affecting the spread of the disease and the health measures employed' (WHO 2005a: Annex 1). At the national level, capacities need to be in place 'to assess all reports of urgent events within 48 hours' and 'to notify WHO immediately through the National IHR Focal point when the assessment indicates the event is notifiable' (WHO 2005a: Annex 1). Moreover, the new regime calls for rather specific response mechanisms (available on a 24-hour basis) to be set in place by governments. This includes, for example, the establishment of a national public health emergency response plan; specialized

multidisciplinary response teams; logistical, technical and personnel on-site assistance to local staff, laboratory facilities; and communication links between different levels and actors (Fidler 2005; Lakoff 2015).

The new regulations also strengthen the role of non-state actors – such as the media, humanitarian nongovernmental organizations, local medical workers, or activists – in disease reporting and they grant WHO more authority in declaring a PHEIC, even without prior consent by the affected state. This extension of epidemic information sourcing beyond traditional (national) public health authorities has been one of the most important changes in recent years: Today, more than 60 per cent of the initial outbreak reports come from unofficial or informal sources.

> Recognizing implicitly the poor performance of formal surveillance systems (i.e. those based on traditional public health infrastructures), WHO has been broadening the data source base for global surveillance by incorporating informal sources of information such as: the mass media, electronic discussion groups, non-governmental and faith-based organizations.
>
> (Calain 2007: 16; see also Davies *et al*. 2015)

Recent, unprecedented advances in the realms of digital health, information technology and artificial intelligence (AI) have fundamentally improved the necessary conditions for global surveillance and made the early detection of infectious diseases far more feasible. In addition to the increased use of electronic medical records, which collect individual health data in a digital form (instead of traditional paper-based records) and speed up the transmission and (if necessary) population-wide analysis of diagnostic results, there is now a number of digital, AI-based notification systems. Applications such as ProMed Mail, the Global Public Health Intelligence Network (GPHIN), Argus, GOARN, HealthMap and others contribute to what WHO calls 'epidemic intelligence' – i.e. the collection of vast amounts of structured and unstructured health-related data. Some of these primarily facilitate the development of a global epistemic community of epidemiologists and disease experts and help to collect and verify information about potential outbreaks. Others for example draw on artificial intelligence and machine learning to detect outbreak patterns: They systematically search and scan publicly available internet sources such as newspapers, radio and TV stations for a large number of disease-related key words to detect patterns that indicate suspicious disease events. The latter tools share two general characteristics: They account for both predefined and unspecified disease events and the occurrence of suspicious syndromes rather than only for known diseases and confirmed laboratory diagnostics; and they circumvent traditional hierarchical information processing of healthcare institutions by using a more network-centric approach based on the collection, analysis and filtering of internet big data, thereby allowing for near real-time disease surveillance.

The fate of Google's highly praised and ambitious Flu Trends project, however, is a cautionary tale against premature expectations: The algorithm-based application was built upon the assumption that non-ordinary health events such as

a flu epidemic are likely to be reflected in people's internet search queries, as those who are affected would search for symptoms, GPs and pharmacies nearby, drugs and the like. Hence, if one could develop an algorithm that would detect increases in those disease-related google searches, one would be able to picture the unfolding disease. 'Unfortunately, Google Flu Trends faltered when it mattered the most, completely missing the onset in April 2009 of the H1N1 pandemic. The algorithm also ran into trouble later on in the pandemic' (Eisenstein 2018). While the algorithm was trained to account for seasonal variations, it did not foresee 'the human component' – i.e. how media coverage and the arising fear of a coming flu would significantly alter people's search behaviour. Moreover, cultural and language barriers often complicate the use of unstructured data, as Moran *et al*. (2016: 406) describe:

> The simplest approach for extracting information from unstructured data, such as tweets, is the bag-of-words approach, in which the frequencies of certain words (or posts containing said words) are tallied. The downfall to this approach is its inability to infer context; the bag-of-words approach cannot tell 'That guy on the bus coughed all over me, and now I have a fever' from 'That concert gave me raging Bieber fever' ...

... a condition affecting predominantly teenage fans of the eponymous pop star.

The global politics of anticipative medicalization

The new international health regulations were designed and implemented to enable 'real-time' detection of (unknown) disease outbreaks by establishing a global disease surveillance and response architecture. Yet the changes go beyond mere institutional adjustments and organizational reforms. Unlike traditional public health measures, which rely on the calculation and assessment of risks and risk factors based on scientific insights on disease etiology and transmission, the new apparatus also targets the unknown, the emergent. The EID concept

> defines infectious disease as *emerging* and *emergent* – not incidentally, but *in essence*. What public health policy needs to mobilize against, the new microbiology argues, is no longer the singular disease with its specific etiology, but *emergence itself*, whatever form it takes, whenever and wherever it happens to actualize.
>
> (Cooper 2008: 80 (emphasis in the original))

The search for outbreaks of known diseases has thus been replaced by the 'aim to recognize abnormal morbidity before knowing what type of morbidity it is, before identifying the disease or its causes' (Samimian-Darash 2013). Introducing the rather vague concept of 'event' was critical in this regard: The term subsumes outbreaks with known causes and those that are initially unexplainable.

This greatly extends the 'radar' of disease surveillance and decouples it from the search for the known.

As indicated, the traditional regime of disease control established in previous international health regulations was replaced by a precautionary 'governance of uncertainty' approach that allows to deal in 'real time' with the emergence of the previously unknown (Figuié 2014). This reflects a significant epistemological change, since it replaces calculations of risks and known disease threats by an emphasis of future uncertainty (with regard to the pathogenic cause and the characteristics of its emergence). Anticipative action is no longer only legitimated on the basis of known, specific threats, but also on the basis of what experts anticipate to potentially materialize. Even more so, it is the very anxiety of the unknown and the perception of a looming future emergency that provide the justification for the establishment of a new mechanism for governing global public health (and vital systems more broadly, as argued by Collier and Lakoff 2015; see also Lentzos and Rose 2009: 247). Ultimately, what we see in the realm of global health is thus the formation of a new 'socio-technical imaginary' (Jasanoff 2015): a publicly shared, institutionally anchored perception of future social life and social order in a world that is characterized by new and uncertain pathogenic developments. This imaginary enabled an 'anticipative medicalization' and justified the construction of a comprehensive global network of big data-driven diagnostic and surveillance technologies.

The reform of WHO's health regulations and institutional response structures has drawn praise from many observers. It was lauded for creating a more effective and efficient system of global health surveillance that better allows to govern the future in global health and to deal with the eventualities of newly emerging diseases (Fidler and Gostin 2006). Less attention has been paid, however, to how the new imaginary also impacts upon and co-constitutes the contemporary sociopolitical and medical order. For example, the significance of the concept of 'Emerging Infectious Disease' is more contested than one might assume. Some authors claim that it is primarily a concern for the western world, while the larger part of the global population suffers rather from a lack of or insufficient sanitary infrastructure, clean water, proper nutrition or from unsatisfactory access to essential medicines. Weir, for example, even asserts that the IHR regime is questionable from a global justice perspective, since the global health security apparatus

> mainly acts to prevent the diseases of the poor people in the South from spreading to the North and laterally to other areas in the South. Bracketing off endemic diseases to construct the domain of global health security is a constitutive exclusion that violates the principles of cosmopolitanism and borderlessness.
>
> (Weir 2015: 27)

The 'harvest of outbreak intelligence overseas is essentially geared to benefit the wealthy nations', as one writer puts it (Blouin Genest 2015; Calain 2007: 19; see also McInnes and Lee 2006).

The virus-sharing controversy between Indonesia and the WHO in 2006 sheds light on a related aspect of this conflict: During the avian (H5N1) influenza outbreak, the country refused to share virus samples with the WHO, complaining that the organization would pass the specimen on to the pharmaceutical industry which would then use it for developing, patenting and selling vaccines without making them also available to less affluent states. This radical move was heavily criticized by many policy-makers and scientists all over the globe and especially in industrialized states (but also backed by many low- and middle-income countries), since it

> threw a sizeable spanner into the global pandemic preparedness machinery because Indonesia was, in many ways, at the 'forefront' of a possible H5N1 pandemic, reporting the highest numbers of human cases and deaths of H5N1 infection up to that point in time. Without access to the viruses circulating within Indonesia's territorial borders, it was no longer possible for the international public health community to acquire comprehensive surveillance data about how the virus was evolving, nor to develop stockpiles of up-to-date candidate vaccines based on the more virulent Indonesian virus strands.
>
> (Elbe 2010: 479; see also Lakoff 2015)

Yet, Indonesia's complaint was not unfounded, other observers maintained. Even the WHO warned that global vaccine production levels were far from sufficient to secure global immunization in times of an influenza pandemic: 'The greatest problem is inadequate production capacity. Demand will unquestionably outstrip supply, particularly at the start of a pandemic' (WHO 2005a: 48). With most vaccine producers being located in the industrialized states of the world, it is easy to infer who would be left standing in case of a global health crisis. Granting all states equal access to the benefits of EID control is a fundamental concern in debates about global health justice.

Contestations of the current conceptualization of EID thus reflect broader struggles over health priorities and resource allocation between western industrialized states and the global South (Weir and Mykhalovskiy 2010: 57). In this vein, critics point to the social and economic causes of pandemics, which, they maintain, are disregarded under the IHR 2005 approach (Keil *et al*. 2011). Relatedly, it has been pointed out that the focus on emerging and reemerging diseases must not distract already scarce resources from long-term, horizontal investments in basic healthcare improvements and disease prevention measures in many states of the South (Calain 2007; Rushton 2011). It is in this spirit that the Director General of WHO, Tedros Adhanom Ghebreyesus, demands to increase efforts at achieving universal health coverage globally:

> Universal health coverage and health emergencies are cousins – two sides of the same coin. Strengthening health systems is the best way to safeguard

> against health crises. Outbreaks are inevitable, but epidemics are not. Strong health systems are our best defence to prevent disease outbreaks from becoming epidemics.
>
> (Ghebreyesus 2017: 839)

Finally, even under the revised IHR and despite the massive advances in digital healthcare and AI, the early assessment of an event's coming pandemic potential remains fraught with uncertainties and intricate decision-making constraints, as the WHO's handling of the H1N1-pandemic in 2009 illustrates: The virus, which is usually only found in pigs, spread rapidly from residents of a Mexican village to the US, Canada and eventually across the globe, and soon prompted horror scenarios of the long-feared deadly pandemic. Triggered by the emergency management of WHO, which declared the outbreak a pandemic of the highest alert level, many wealthier states soon began to procure and store millions of doses of antiviral medication (e.g. 'Tamiflu'). Eventually, the epidemic turned out to be less severe than expected, leading to sharp criticism of the organization's decision-making (Davies and Youde 2015; Doshi 2011; Keil *et al*. 2011; Lakoff 2015).

This episode indicates that the anticipation of 'future health', i.e. the trajectory of emerging diseases is 'subjected not only to the epistemic uncertainties of predictive knowledge, but also to political and economic constraints and imperatives, local and international contexts, the individual experience of risk managers and the availability of control options' (Seetoh *et al*. 2012: 49) – and it is also subjected to decision-makers seeking to 'manage the risks of being wrong about risks' (Dunn Cavelty 2020). Governing the future, whether in health or other policy fields, is thus never merely a value-free, rational assessment of factual knowledge. Instrumental reasons, interests and policy-agendas also come into play, when experts, politicians and decision-makers pick from and act upon a range of possible future health scenarios. Whether false alarms and inflated scares will lead to 'contagion exhaustion' (Osterholm 2013) and diminished alertness remains to be seen. Perhaps it is, to the contrary, even an essential feature of pandemic prophecies that they are always 'on the verge of happening', as Caduff writes: 'In the prophetic scene, people are constantly confronted with the never-quite-arriving point of the disease, a disease that remains on the horizon as a dark prospect' (Caduff 2015: 23).

Conclusion

Because of the fragility and finitude of human life, the desire to envision and control our future health and physical integrity is perhaps particularly urgent and deep. The examples presented in this chapter suggest that we are currently witnessing an increasing anticipative medicalization of life: an expansion of diagnostic and surveillance technologies designed to facilitate the governing and management of imminent or future illnesses. This development is strongly interlinked with the rise of big data, digital technologies and AI in healthcare,

which allow for the massive collection, processing and analysis of structured and unstructured health data on an individual as well as on a population-wide level.

With regard to personal health, the novel tools of testing and engineering have spurred a fundamentally new perception of genetic inheritance and genetic potentiality and have grown from a niche-tool to a standard application for clinical and lifestyle purposes in wealthy societies. Individuals are now increasingly encouraged and perhaps even impelled to find out their genetic health risks and to manage their bodies and reproductive choices accordingly and preventively. How the prediction and management of risks will play out in future biopolitics and whether this will lead to a manifest moral or economic imperative to behave like a 'good genetic citizen' is not yet readily visible. Likewise, many ethical questions remain regarding data ownership, security and access. Biotechnological progress has been so fast and far-reaching, though, that states' attempts to regulate and govern these new technologies as well as the societal discourse on their implications, are repeatedly outpaced.

On the global level, envisioning future health plays out differently, since research on the precise prediction of communicable disease outbreaks is still in an early stage. And yet, we can observe a similar trend towards data-driven anticipative medicalization: Facilitated by the unparalleled advances in digital health and AI and the vast increase in health data that is generated today, the lauded IHR-system of communicable disease surveillance helps to detect disease outbreaks of international concern in real-time. Arguably, the novel mechanisms that move the governing of uncertainty centre stage are not limited to the specific handling of certain diseases, but leave a strong imprint on the present global health order: As an analysis of the regulations shows, governing the potential future event is now as important as the management and mitigation of already existing challenges. The IHR 2005 reflect the assumption that it is not necessarily the long-known diseases that present the severest danger, but that the public must be equally protected from the 'unknown' and the 'newly emerging' that can happen anytime.

A specific vision of the future has thus become one of the crucial reference points for shaping current structures of global public health policy. The case of the health regulations exemplifies, how a new scientific imaginary of the future gained authority and consequently was applied to negotiate and establish a new order for the effective governance of global public health. But in global public health, too, many ethical questions remain: Who owns the health data – ranging from data collected through electronic medical records, diagnostic tests, clinical trials, wearables or mobile devices to environmental and geospatial data? How can we make sure that commercial business models do not preclude data use for public health purposes? How can we bridge the still existing digital divide? How can data misuse, privacy breaches and fraud be prevented? How can we reconcile the rights and interests of different stakeholders – for example of individuals, public health and state authorities, business companies? How can we guarantee that the benefits of the new technological advances are distributed

equally across the globe? Since the current move towards big data, digitalization and AI happens at such fast speed, many states lack the capacities and the expertise to develop needed regulatory frameworks. Global efforts will thus be needed to make sure that the technologies to govern the emerging 'health future' are implemented responsibly.

Even though the mechanisms and procedures at the individual and the global level diverge, they seem to be driven by a larger, unifying imaginary that appears characteristic for our dealings with life in the twenty-first century: a growing desire to anticipate and reign over our future health by augmenting the scope, functionality and applicability of biotechnological tools and practices of predictive diagnostics and surveillance.

Notes

1 Work on this chapter was completed before the emergence of Covid-19.
2 Conrad and Waggoner introduced the term 'anticipatory medicalization', but their usage differs from the one I suggest here: They are primarily concerned with the broadening of medical conditions and their underlying definitions which lead to an increase in the number of patients being diagnosed and treated for a specific disorder, while I address the expansion of predictive and surveillance techniques for covering future health eventualities (Conrad and Waggoner 2017). Elbe, on the other hand, uses the term 'medicalization' (of insecurity) to describe how medical reason is increasingly applied to issues of international and global security (Elbe 2012).
3 While this chapter focuses on genetic testing and diagnostics in individual health, the turn towards prediction of individual disease risks is not limited to this realm. There are now abundant examples that indicate the potential of predictive tools if they are combined with the large amounts of regularly collected population-wide medical data. For instance, in Israel – a pioneer in the application of digital technologies in healthcare – large-scale 'predictive data mining' based on algorithms is already used by health insurance companies to search for and identify disease patterns and risk distributions among groups or to individualize and specify therapeutic interventions to single patients based, for instance, on calculated risks due to secondary conditions (Balicer and Afek 2017). The combination of large amounts of data and predictive algorithms enables insurers to specifically predict the risk of individual applicants and to design more precise risk classification (and payment schemes) systems for the insured. At the same time such tools allow to incentivize 'good behaviour' (and penalize unhealthy lifestyles) based on calculated preconditions and risks of falling ill.
4 Why these pandemic prophecies became particularly appealing and authoritative in the US context goes beyond the confines of this chapter. Caduff makes a convincing argument, though, that notions of a looming existential threat are deeply anchored in a long tradition of apocalyptic thought that remains present in the American history of ideas (Caduff 2015: 5).

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