

**NUFFIELD  
COUNCIL<sup>ON</sup>  
BIOETHICS**

**BACKGROUND PAPER**

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**Pandemics**

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Agency*

**Forward Look  
19-20 May 2011**

**Note**

The authors were commissioned by the Nuffield Council on Bioethics to write this paper in order to inform the Council's discussions about possible future work on this topic. The paper is intended to provide an overview of key clinical, ethical, social, legal and policy issues, but is not intended to offer any conclusions or recommendations regarding future policy and practice. Any views expressed in the paper are the views of the authors and not those of the Nuffield Council on Bioethics.

# NUFFIELD COUNCIL ON BIOETHICS

*Forward Look  
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## **Pandemics**

### **Background Paper**

*Giovanni De Grandis, University College London  
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#### **Summary**

- 1 This paper highlights the main ethical problems raised by strategies aiming at pandemic prevention and control. It outlines what issues nations, policy makers, health care professionals and the public are faced with both during a pandemic and in the attempt to stave it off.

#### **Background**

##### ***Historical***

- 2 While efforts to prevent the spread of deadly epidemics – plagues, as they were called – can be traced back to the introduction of quarantines in the Middle Ages,<sup>1</sup> pandemics have become the subject of preventive attention and efforts only in the 19<sup>th</sup> century, when a series of dreaded epidemics of cholera managed to spread from India worldwide, causing death, horror and international controversy on how to restrict the spread of disease.<sup>2</sup> The first International Sanitary Conference took place in Paris in July 1851 and 13 more followed. The experience of these conferences was fundamental in eventually setting up the WHO in 1948.<sup>3</sup> However, pandemics have not been one of the central concerns of the WHO until recently. This is in part the result of a more general concern about new and emerging infectious diseases, and of the risk of bioterrorism.<sup>4</sup> Events that have particularly contributed to call attention specifically to the risk of

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<sup>1</sup> Cipolla, CM (1976) *Public Health and the Medical Profession in the Renaissance* (Cambridge: Cambridge University Press); McNeill W (1977) *Plagues and People* (New York: Anchor Doubleday); Harrison M (2004) *Disease and the Modern World. 1500 to the Present* (Cambridge UK: Polity Press).

<sup>2</sup> Harrison 2004 op.cit.; McNeill 1977 op.cit. ; Fidler DP (2001) The Globalization of Public Health: The first 100 Years of International Health Diplomacy *Bulletin of the World Health Organization* **79**(9): 842-9, available at: <http://ocp.hul.harvard.edu/contagion/sanitaryconferences.html>.

<sup>3</sup> Fidler DP (2004) Germs, Governance, and Global Public Health in the Wake of SARS *The Journal of Clinical Investigation* **113**(6): 799-804; Huber V (2006) The Unification of the Globe by Disease? The International Sanitary Conferences on Cholera 1851-1894 *The Historical Journal* **49**(2): 453-76.

<sup>4</sup> Enemark C (2006) Securitized Infectious Diseases, in Selgelid M, Battin MP, and Smith CB (eds) *Ethics and Infectious Disease* (Malden and Oxford: Blackwell: 327-343); Davies SE (2009) *Global Politics of Health* (Cambridge UK: Polity Press).

pandemics include the HIV/AIDS pandemic, the SARS outbreak in 2003 and the fear of a new pandemic influenza. A noteworthy result of the renewed attention towards the risk of deadly infectious diseases with a pandemic potential is the establishment in 2005 of the Global Outbreak Alert and Response Network (GOARN).<sup>5</sup> At a national level, all Western countries now have pandemic influenza plans recently prepared or updated and most of these are available to the public. The situation is much less satisfactory in developing countries.<sup>6</sup> Remarkably so far planning has focused almost exclusively on influenza and (to some extent) bioterrorism.

### **Sociobiological**

- 3 Significantly the first International Sanitary Conference took place in the same year in which the first International Exhibition was celebrated. The international epidemics of cholera and yellow fever were the upshot of an age of great technological innovations and of major economic and social transformation, and in particular of the unprecedented progresses of international commerce, transport and communication. Infectious diseases had already begun their process of globalisation many centuries earlier, but the technological progress associated with the industrial revolution, railways and steamboats inaugurated an age in which infection could spread as quickly and widely as never before. This was in Le Roy Ladurie memorable phrase: 'the unification of the globe by disease'.<sup>7</sup>
- 4 As the origins of global public health remind us, the potential for the global spread of an infectious disease is a combination of biological and social circumstances.<sup>8</sup> It takes a pathogen that can live and be communicated in all climates, but it also takes a human population that is sufficiently dense to support the disease and sufficiently connected to pass it on from one group to the next (or alternatively a vector that can reach all human populations). The growth of human population and density together with global trade and fast transportation have firmly established the social conditions that can enable a pandemic to take place and to spread fast if unchecked by prompt public health measures.
- 5 The social circumstances necessary for the occurrence of a pandemic are well established features of the contemporary world characterised by global trade and fast international mass transports. On the other hand, the biological circumstances represent the variable circumstance: the occurrence of a pandemic, or of a pandemic threat, depends on the presence of a suitable pathogen. Such a pathogen could be either an

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<sup>5</sup> WHO <http://www.who.int/csr/outbreaknetwork/en/>; Davies 2009 op.cit.: 150-5.

<sup>6</sup> Battin MP, Francis LP, Jacobson JA, & Smith CB (2008) *The Patient as Vector and Victim* (New York: Oxford University Press): 336-7; WHO, <http://www.who.int/csr/disease/influenza/nationalpandemic/en/index.html> ; PandemicWatch Canada, <http://microbiology.mtsinai.on.ca/avian/all-pandemic-plans.asp>; ECDC, [http://ecdc.europa.eu/en/healthtopics/pandemic\\_preparedness/national\\_pandemic\\_preparedness\\_plans/pages/national\\_pandemic\\_preparedness\\_plans.aspx](http://ecdc.europa.eu/en/healthtopics/pandemic_preparedness/national_pandemic_preparedness_plans/pages/national_pandemic_preparedness_plans.aspx)

<sup>7</sup> Le Roy Ladurie E (1973) Un concept: l'unification microbienne du monde (XIVe-XVIIe). *Revue Suisse d'Histoire* 4: 627-696

<sup>8</sup> Cf. Whitman J (2000) Political Processes and Infectious Diseases, in idem (ed) *The Politics of Emerging and Resurgent Infectious Diseases* (London: Palgrave MacMillan: pp. 1-14).

already known one (re-emergent disease) or a new one (emerging disease). It seems therefore that the possibility of a pandemic depends on one of the following scenarios:

- a) the ability of a known pathogen to overcome the constraints that presently keep it under control, be they (1) natural, or (2) medical, or (3) public health factors;
- b) the appearance of a new pathogen capable of living and infecting under most climates and to either (i) spread from person to person, or (ii) to find a worldwide spread vector.

6 Unfortunately, the present circumstances afford some opportunities for both (a) and (b). Changes in behaviour and lifestyle, breakdowns in public health measures and deteriorating public health infrastructures, modern medical, farming and food processing practices (in particular the misuse of antibiotic and antimicrobial drugs), and finally microbial adaptation and mutation, travel and migration, bioterrorism are the main factors that can favour the re-emergence of known pathogens and may enable them to reach pandemic dimensions. Environmental degradation, increased penetration in tropical forests, climate change, increased urbanization and crowding are – together with some of the factors already mentioned – the most likely causes of the emergence of new pathogens with the potential of causing a pandemic.<sup>9</sup>

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<sup>9</sup> Lederberg J, Schope RE & Oaks SC Jr (eds) (1992) *Emerging infections: Microbial threats to health in the United States* (Washington, DC: National Academy Press); Morse SS (1995) Factors in the Emergence of Infectious Diseases *Emerging Infectious Diseases* 1(1): 7-15; Cohen ML (1998) Resurgent and emergent disease in a changing world *British Medical Bulletin* 54(3): 523-532; Lederberg J (2001) Summary and Assessment, in Davis JR & Lederberg J (eds) *Emerging Infectious Diseases from the Global to the Local Perspective* (Washington DC: National Academy Press: 1-28); Brower & Chalk 2003 op.cit.; Kaufmann SHE (2009) *The New Plagues. Pandemics and Poverty in a Globalized World*, translated by Capone M (London: Haus Publishing) Ch. 10. The role of the deterioration of public health infrastructures and programmes has been recognised as a very important factor since infectious diseases commanded renewed attention in the West. The landmark report published by the IOM (Lederberg, Shope & Oaks 1992) led the way (see pp. 7-8, table 2.1 pp. 36 ff., pp. 106-12) and was followed by almost every subsequent document. The deterioration of public health in the USA had been exposed 4 years earlier in a famous report —IOM (1988) *The Future of Public Health* (Washington DC: National Academy Press). The updated published in 2002—IOM (2002) *The Future of the Public Health in the 21st Century* (Washington DC: National Academy Press)—shows that public health still suffers several problems and inadequacies (p. 3). A forceful case for the inadequacies of public health worldwide and a richly document illustration of the disastrous outcomes of collapses of public health are found in Garrett L (2001) *Betrayal of Trust* (Oxford: Oxford University Press).

## Features of Pandemics

### *Infectious diseases, plagues and pandemics: clearing the ground*

- 7 When the issue of emerging and re-emerging infectious diseases gained public attention, the word that was most frequently used was (and still is) *plague*.<sup>10</sup> This use is explained by its rhetorical and emotional impact, yet it is useful to highlight an important difference between the concepts of '*plague*' and that of '*pandemic*'. While the former stresses the deadliness, psychological horror and social disruption that a mortal disease brings about, the latter stresses the global diffusion of a disease. This may explain why the latest WHO directives on pandemic influenza detection and preparedness focus on the pattern of diffusion rather than the severity and lethality of the virus.<sup>11</sup> While this emphasis may help in stressing the difference between the concepts of plague and pandemic, it has, however, become so broad and generic as to make it difficult to delineate clearly what marks a pandemic as special.
- 8 The obvious and uncontested feature of a pandemic is its *actual* or *potential* global diffusion. Were this the only defining feature of a pandemic, it could be understood as a disease either globally epidemic or endemic worldwide. In fact, however, 'pandemic' is usually understood to mean 'global epidemic'.<sup>12</sup> Yet it is not uncommon that a global disease is endemic in some areas and epidemic in others – e.g. AIDS is nowadays endemic in developed countries and epidemic in many developing countries, while measles is endemic in poor countries and only give rise to occasional epidemic outbreaks in developed countries. This shows that whether or not to consider a given disease a pandemic may reflect local interests and geopolitical biases. With this caveat, we will use 'pandemic' as meaning *global epidemic*, following thus the prevailing use. Furthermore, we limit the use of the concept to *infectious or communicable diseases*, thus ruling out the use of pandemic with reference to conditions such as obesity and diabetes. The reasons for such a limitation are mainly pragmatic: from the point of view of ethics and policy-making, the concept of pandemic is useful if it helps to single out a

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<sup>10</sup> Garrett L (1994) *The Coming Plague. Newly Emerging Diseases in a World out of Balance* (New York: Farrar Strauss & Giroux); Karlen, A (1996) *Plague's Progress. A Social History of Man and Disease* (London: Indigo); Wills C (1997) *Plagues. Their Origins, History and Future* (London: Flamingo); Farmer P (2001) *Infections and Inequalities: The Modern Plagues* (Berkeley: University of California Press); Walters MJ (2003) *Six Modern Plagues: and How We Are Causing Them* (Washington-Covelo-London: Island Press); Kaufmann 2009 op.cit.; Oldstone MBA (2010) *Viruses, Plagues, & History. Past, Present and Future* (New York: Oxford University Press).

<sup>11</sup> See WHO (2009) *Pandemic Influenza Preparedness and Response* (Geneva: WHO), pp. 22-7. Some media contended that WHO no longer included high morbidity and mortality as necessary conditions for a pandemic, see for instance <http://www.spiegel.de/international/world/0,1518,637119,00.html> The WHO has replied to this that severity is too dependent a variable to provide a useful standard, although this does not mean that it is not important and in fact excess mortality is always to be expected (see [http://www.who.int/csr/disease/swineflu/notes/briefing\\_20100610/en/](http://www.who.int/csr/disease/swineflu/notes/briefing_20100610/en/) sub point 5).

<sup>12</sup> <http://www.who.int/csr/disease/influenza/pandemic/en/>. Cf. definitions in: Porta M (ed) (2008) *A Dictionary of Epidemiology*. Fifth Edition (Oxford: Oxford University Press) p. 179; Kaufmann 2009 op.cit. p. 56; Sattenspiel L (2009) *The Geographic Spread of Infectious Diseases. Models and Applications* (Princeton NJ and Woodstock UK: Princeton University Press) p. 15. While the latter authors include the condition that the epidemic becomes global within a short time, the former does not. This is an important disagreement that is reflected in current use and that makes an important difference on which diseases count as pandemic.

distinctive set of issues that are not simply a duplicate of those raised by public health ethics or of the ethics of infectious diseases more generally.

### ***The distinctive features of pandemic ethics and policy***

- 9 It is possible to single out some distinctive issues especially associated with pandemics. The most obvious is (1) that the global dimension (or potential dimension) of pandemics raises questions related to their international dimension. This is obvious but not trivial, especially from the point of view of public health, which has typically a national dimension and is rooted in state action and institutions, in the system of the welfare state, in the notion of the common good of a specific community, and in citizenship rights and entitlements.<sup>13</sup> Only states have the authority and power to implement the measures that may contain the spread of a disease through the control of the environment and of the host, but they cannot control the pathogen without international cooperation and agreements.<sup>14</sup> While issues of international cooperation are not exclusive to disease with global diffusion, these latter raise them more acutely. The impact of severe epidemics on human communities and states has been often stressed and there is growing literature that brings infectious diseases under the umbrella of national security.<sup>15</sup> But seen as a threat to national security severe infections may require the exercise of the full sovereign power of the state. It follows that an acute tension between international cooperation and national self-interest and sovereignty is likely to occur, especially in areas of pre-existing international tensions.<sup>16</sup> Hence the ultimate test of international agreements,

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<sup>13</sup> Cf. Rosen G (1992) *A History of Public Health. Expanded Edition* (Baltimore and London: The Johns Hopkins University Press); de Swaan A (1988) *In Care of the State. Health Care, Education and Welfare in Europe and the USA in the Modern Era* (Cambridge UK: Polity Press); Porter D (1999) *Health, Civilization and the State. A History of Public Health from Ancient to Modern Times* (London: Routledge).

<sup>14</sup> WHO (2008) *International Health Regulations 2005. 2nd Edition* [http://whqlibdoc.who.int/publications/2008/9789241580410\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241580410_eng.pdf); Fidler 2004 op.cit.; Gostin LO & Berkman BE (2007) *Pandemic Influenza: Ethics, Law, and the Public's Health* *Administrative Law Review* 59: 121-175.

<sup>15</sup> On the historical impact of infectious diseases see Zinnser H (2002) *Rats, Lice and History* (New Brunswick NJ and London UK: Transaction Publishers); Cartwright FF & Biddis MD (2004) *Disease and History* (Stroud: Sutton); McNeill 1977 op.cit.; Hobhouse H (2005) *Forces of Change. An Unorthodox view of History* (Berkeley: Shoemaker and Hoard) ch 1; Harrison M (2004) *Disease and the Modern World. 1500 to the Present* (Cambridge UK: Polity Press); Oldstone 2010 op.cit. On the trend to consider infectious diseases as national security issues see Garrett L (1996) *The Return of Infectious Disease* *Foreign Affairs* 75(1): 66-79; Brundtland GH (2003) *Global Health and International Security* *Global Governance* 9: 417-23; Brower & Chalk 2003 op.cit.; Enemark 2006 op.cit.; McInnes C & Lee K (2006) *Health, Security and Foreign Policy* *Review of International Studies* 32(1): 5-23; Davies SE (2008) *Securitizing Infectious Disease* *International Affairs* 84(2): 295-313; Davies 2009 op.cit., Price-Smith AT (2009) *Contagion and Chaos. Disease, Ecology, and National Security in the Era of Globalization* (Cambridge MA and London UK: MIT Press).

<sup>16</sup> There are interesting historical examples of internal and international tensions caused by epidemics or pandemics. See Ackernecht EH (1948) *Anticontagionism between 1821 and 1867*. *Bulletin of the History of Medicine* 22(5): 562-93; Harrison 2004 op.cit.; Hamlin C (2009) *Cholera. The Biography* (Oxford: Oxford University Press); Price-Smith AT (2001) *The Health of Nations. Infectious Disease, Environmental Change, and their Effects on National Security and Development* (Cambridge MA and London UK: MIT Press); Price-Smith 2009 op.cit.. Price-Smith highlights many of the strains that severe outbreak may have on governments. An example is the irrationality and xenophobia that can impair decision-making and breed hostility and conflict. Increasing deprivation and frustration caused by the spread of disease can breed aggression, violence and chaos. Another problem is that an effective network of prevention and surveillance of the many diseases that can spread widely would require enormous amounts of political will, international cooperation, continued regime consolidation, and a significant redistribution of resources from the

strategies and cooperation is their ability to tackle pandemics and to overcome the jealous control that states exercise over their sovereign power.<sup>17</sup> Moreover, as compared to diseases with only a regional diffusion, they involve a higher degree of cultural, economic and geopolitical diversity.

- 10 A further element of distinction is (2) the breadth and depth of consequences of a pandemic. This is not a question of the absolute burden of disease, for a pandemic may cause a lower death toll and the loss of fewer DALYs or QALYs than a severe localised epidemic.<sup>18</sup> Rather, the difference is that during a pandemic every community is under threat and under stress; as a consequence, mutual reliability too is stressed and dependence on other countries for the supply of resources (e.g. vaccines) becomes problematic. The global dimension of disease creates both a commonality of needs and a competition for the limited resources available.<sup>19</sup> Cooperation is both needed and difficult. This is reflected also at the level of national public health authorities: they are caught in a conflict between a humanitarian imperative to act in the global interest and a special obligation and accountability to the community they serve. Moreover a pandemic is expected to have a considerable adverse impact on the productivity of all nations affected and on global trade: this can further compromise the resources and governance capacity of poor and ineffective states.
- 11 The combination of (1) and (2) may cause further problems. The level of cooperation required is very high and there are few examples of successful cooperation when serious national and security interests are at stake. There are several obstacles to overcome. National pride and interests may get in the way of open disclosure of information, and this tendency will be exacerbated in countries where information flows are routinely controlled by central government. Sharing information may have negative effect on the country (e.g. export, tourism) or may be perceived as a bargaining asset in the attempt to receive help and support from more developed states. It is therefore important that international agreements and cooperation schemes take into account

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developed to the developing countries' (2001, p. 16). In the face of such challenges he laments that 'there are no substantive international mechanisms to ensure the cooperation of sovereign states' (2009, p. 84). He thus concludes that 'In the context of such weak international institutions, and with states serving their own material self-interests, we are likely to see less than optimal international cooperation in the face of highly pathogenic pandemic influenza' (2009, p. 85).

<sup>17</sup> On the lasting strength of the doctrine of sovereignty in spite of globalization and of the growth of international institutions and agreements see Fowler MR & Bunck JM. (1995) *Law, Power, and The Sovereign State* (University Park PA: The Pennsylvania State University Press); Jackson R (2007) *Sovereignty* (Cambridge UK and Malden Ma: Polity); Calhoun C (2007) *Nations Matter. Culture, History, and the Cosmopolitan Dream* (London and New York: Routledge).

<sup>18</sup> QALY stands for Quality Adjusted Life Years, while DALY means Disability Adjusted Life Years. Both measures try to capture not only the impact of diseases (or health measures) on mortality, but also the broader consequences on the welfare, lifestyle and special needs of people affected. In not merely considering (remaining) life expectancy but also adding a measure of life quality, they seek to provide a more comprehensive concept of health status. This should afford a more accurate appraisal of the impact of diseases and health intervention. For instance a simple mortality measure would not capture the impact of a polio epidemic that leaves several young people permanently disabled, while this outcome would be registered by measuring QALYs or DALYs lost.

<sup>19</sup> Kaufmann 2009 op.cit., p. 265; Gadd EM (2010) *Ethical Issues Related to Pandemic Preparedness and Response*, in Van-Tam J & Sellwod C, *Introduction to Pandemic Influenza* (Wallingford UK and Cambridge Ma: CAB International: 171-81), p. 173.

these problems and try to create a proper structure of incentives rather than relying only on lofty ethical considerations.

- 12 From a pandemic's potential seriousness and disruptiveness follows another peculiar feature of pandemics: (3) they are diseases that concern the public and public health authorities even when they are not there. Facing a pandemic requires preparedness and preparedness in turn demands surveillance and prevention, i.e. actions that need to be carried out *before* the disease is there. Pandemics enter the domain of public health as eventualities before entering it as realities. Pandemics more than any other kind of disease have a *virtual* existence apart from having any actual existence. This means that preventive measures are taken against a threat that is unknown. Precaution and preparation are carried out on the basis of forecasts, anticipations and modelling and therefore a good deal of policy-making concerning pandemics takes place in circumstances of great uncertainty, in which risks and benefits are highly hypothetical. To be sure, uncertainty is almost ubiquitous in the health domain, for outcomes of interventions are typically uncertain. But in the case of pandemics uncertainty is not limited to the prognosis, nor simply extended to the diagnosis: it is the pathological event in itself that is purely virtual. Given that the hypothetical event is not one concerning an individual, but spreading over the world population, the contrast between the largeness of the scale and the poverty of the certainty is striking and a distinctive feature of pandemics. Preparedness for a large scale and potentially disastrous event cannot be a trifle, and yet it has to be based on highly uncertain predictions. The uncertainty includes the occurrence, the time and the nature of the event, a kind of uncertainty that can make preparation completely misplaced and wasteful. In advance, almost everything is unknown: aetiology, infectiousness, mode of transmission, mortality rate, virulence, epidemiology.
- 13 A closely related feature of pandemics is that (4) they require both advance planning and the management of the unavoidable and constant readjustment of plans to suit the actual circumstances: the actual (and evolving) geo-epidemiology of the contagion, people's behaviour and emotional reactions, levels of social compliance with public health measures, health care workers' levels of morbidity and of performance, eventual medical progresses in treatment and towards immunization, level of disruption in public services and infrastructures etc. Advance planning is essential in order to have the required infrastructure, capabilities and guidelines to tackle the pandemic, but at the same time every plan and model is unlikely to match perfectly the reality of the event. A structure with the authority and capability to exercise a constant and swift realignment of plans to changing needs and possibilities is required if planning is not to turn into a counterproductive straightjacket.<sup>20</sup>

## **Ethics and Policy - Pandemic Preparedness**

### ***Uncertainty***

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<sup>20</sup> It is impossible to judge the best course of action until the exact characteristics of a pandemic are known' (Gadd 2010 op.cit., p. 175). 'Much is uncertain in pandemic planning, and much is at stake, so ongoing mechanisms for reassessment are essential' (Battin et al 2009 op.cit., p. 340).



- 14 As already stressed, unpredictability and uncertainty surround the emergence of pandemic threats. Even in the case of one specific disease with a well known pandemic potential, influenza, we find examples of highly overestimated risks – H1N1 in 2009-10 – as well as fully unexpected health disasters ("Spanish Flu" in 1918). In spite of years of study and monitoring, we only know that a pandemic influenza should be expected, but we cannot tell when and how hard it will strike. Uncertainty is obviously still higher with new diseases and the impact can vary widely as SARS and HIV/AIDS graphically show.

## **Surveillance**

- 15 Surveillance in pandemic preparedness refers to all those methods of health intelligence that monitor incidence and prevalence of potentially pandemic diseases. Surveillance uses a range of available data, depending on availability and the quality of data sets. Among them are mortality statistics, laboratory confirmed cases of infection, absence from work-data, or hospital admissions.<sup>21</sup> In the UK, surveillance is mainly carried out by the Health Protection Agency (HPA) which has established reference laboratories for confirmation of infectious diseases and alerts policy makers in the case of new outbreaks or sudden spikes in incidence.<sup>22</sup> Surveillance is not only relevant in the interpandemic period but also during an outbreak, in order to assess the course of the disease, identify high risk groups and collect data for the post-pandemic assessment.<sup>23</sup>
- 16 There have been concerns regarding the partial suspension of patients' rights to privacy in the case of pandemic surveillance. If physicians diagnose an infectious disease which is deemed to be highly contagious and has epidemic or pandemic potential, they are obliged to report it to the HPA. Furthermore, many countries carry out unlinked testing for infectious diseases such as HIV/AIDS to monitor prevalence. In some cases, however, this has happened without explicit patient consent.<sup>24</sup> Furthermore, new approaches to surveillance, so called 'syndromic' methods, work by accumulating data of symptoms and looking for clusters before the onset of a pandemic. Such methods require the routine collection and pooling of large amounts of patient data, making the issue of privacy infringement and lack of express consent even more pressing.<sup>25</sup>
- 17 Surveillance also raises ethical questions on a global scale. Since infectious diseases do not respect national borders, it is generally expected that countries co-operate on the exchange of surveillance data. However, cooperation in other areas of pandemic policy-making raises issues of reciprocity. Shall only information be pooled or preventive and health care resources as well? This is the question raised by Indonesia's controversial refusal to share data during the H1N1 pandemic in 2009-2010. Indonesia authorities claimed that they would have shared data only if developed countries had shared vaccine. The benefits as well as the burdens of surveillance had to be shared, they

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<sup>21</sup> Van-Tam, J Seasonal Influenza: Epidemiology, Clinical Features and Surveillance, in Van-Tam J. and C. Sellwood (eds.) (2010) Introduction to pandemic influenza: 9-11

<sup>22</sup> Health Protection Agency (2010) The role of the Health Protection Agency in the "containment phase" during the first wave of pandemic influenza in England in 2009 available at: [www.hpa.gov.uk](http://www.hpa.gov.uk)

<sup>23</sup> *ibid.*

<sup>24</sup> Kessel A, Watts C, Weiss H (2000) Bad blood? Survey of public' views on unlinked anonymous testing of blood for HIV and other diseases, *BMJ*, 320:90-1

<sup>25</sup> Francis, L et al (2009) Syndromic Surveillance and Patients as Victims and Vectors, *Bioethical Inquiry* 6: 187-195

claimed.<sup>26</sup> Surveillance also raises questions of trust between countries. In some cases, the WHO has rejected official data as unrealistic and politically motivated.<sup>27</sup>

## **Modelling**

- 18 Pandemic planning relies on anticipating the course that a pandemic infection will take. This requires a prediction of the future spread, the social groups who will be most affected, and an assessment of the effect that counter measures such as vaccinations may have. Modelling is a mathematical technique that uses statistical tools of varying complexity to simulate socio-demographic structures and interaction between people, so as to foresee the speed of transmission.<sup>28</sup> It is employed both on a national level (e.g. by the HPA) as well as within supranational organisations such as the European Centre for Disease Control (ECDC) and the WHO. Modelling is crucial to policy making, as it offers an estimate of what health care systems and societies should prepare for. However, the use of models is contentious for a number of reasons.
- 19 The biggest problem of modelling in infectious disease control is understanding what models can and cannot do. A model is essentially a calculation of what will happen in a representative society, given a number of assumptions. Models are not built or employed in isolation. They require that parameters such as transmission rates, lethality of a pathogen or incubation period are predefined. In pandemic scenarios, where reliable information is scarce in the early stages, a reliable provision of such input parameters may not be possible. A model is thus only as good as the quality of the parameters it is based on, and if this is not taken into account, there is a risk of overestimating the validity of forecasts that are developed with the help of statistical model. This is especially true, if modelling techniques aren't well understood by policy makers and the methodology is treated like a 'black box'. Hence, models are only a reliable tool of forecasting on the assumption that the predefined parameters are accurate. For example, a recommendation to vaccinate a certain proportion of the population based on the findings of a model will only be useful, if the assumptions regarding ease of transmission and effectiveness of the vaccine are good estimates. This matter is further complicated by the fact that such parameters may change over the course of a pandemic, for example if the pathogens undergoes mutation, or weather conditions become more or less favourable to rapid transmission in the case of airborne diseases.
- 20 From an ethical perspective it is therefore important to establish when and how models can be used to forecast the development of pandemics, and what decisions should be based on the findings of mathematical models. Most importantly, however, it is crucial that all parties involved in decision-making are fully informed about the usefulness as well as the limits of mathematical modelling.

## **Cost-benefit analysis in pandemic preparedness**

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<sup>26</sup> Fidler, D. (2009) Viral Sovereignty, Global Governance, and the IHR 2005: The H5N1 Virus Sharing Controversy and its Implications for Global Health Governance', in IOM, Infectious disease movement in a borderless world, The National Academies Press, Washington, DC: 210-228; Kaufmann (2009), op. cit., pp. 264-265.

<sup>27</sup> WHO (2010) Global Tuberculosis Control 2010 (Geneva: WHO Press)

<sup>28</sup> See Vynnycky E, White R (2010) Introduction to Infectious Disease Modelling (Oxford:OUP)

- 21 So far it has been shown that pandemic planners operate under far-reaching conditions of uncertainty regarding the danger and timing of future pandemics. Given that pandemic preparedness is a part of the provision of health care, however, policy makers are regularly forced to make decisions regarding the appropriate level of pandemic preparedness or – in the case of an outbreak – pandemic response. As health care resources are limited, a decision to invest more into pandemic preparedness will inevitably incur opportunity costs which means that alternative options to invest money are no longer available. The challenge is thus to define 'the right amount' of expenditure on pandemic preparedness.
- 22 The value that societies place on protection against future health threats is unlikely to be universal, meaning that every pandemic planning agency needs to address the question for the population under consideration. In policy areas other than pandemic planning, economic theory has attempted to elicit group preferences by measuring willingness-to-pay (WTP), which is essentially a survey designed to find out, how much people value the reduction of a given risk in monetary terms, thereby defining a socially optimal level of spending. This is a particular common method in establishing expenditure levels for safety features in public transport.<sup>29</sup> However, evidence suggests that WTP approaches do not lend themselves to establishing expenditure on infectious disease prevention, as the trade-off people are faced with is so complex and involves so many elements of uncertainty, that surveys do not produce internally consistent findings.<sup>30</sup> Furthermore, it must be noted that pandemics fall into the category of dread-risks. Dread-risks are usually large scale catastrophic events that occur infrequently and with low probability but with dramatic consequences.<sup>31</sup> Whilst statistically no more likely to affect the individual, most people overestimate the likeliness of dread risks. Consequently, any calculation of societal preferences must take into account that people may harbour greater fear of pandemics and their outcome than may be rational in light of statistical odds.<sup>32</sup>
- 23 Even if societies can agree on the right amount of overall expenditure on pandemic preparedness, however, it remains unclear in what order the available resources should be made available to the public. Many pandemic plans include lists of patient groups that will be prioritized for receiving vaccination. There is - again - no universally applicable method of prioritizing patient groups and it will therefore depend on society's value judgements to establish the order in which people should receive treatment or vaccination. Such decisions may range from triage in the case of a bioterrorist attack, to allocation of ventilators or ICU beds, to prioritization for influenza vaccine (this last being included in UK planning documents).<sup>33</sup>

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<sup>29</sup> See e.g. Jones-Lee, M. et al (1998) On the Contingent Valuation of Safety and the Safety of Contingent Valuation: Part 1, *Journal of Risk and Uncertainty*, 17: 5-25

<sup>30</sup> Mangtani P, Shah A (2006) The socio-economic burden of influenza: costs of illness and "willingness to pay" in a publicly funded health care system', in Roberts, J (ed.), *The Economics of Infectious Disease* (Oxford:OUP): 159-181

<sup>31</sup> Gigerenzer, G (2006) Out of the Frying Pan into the Fire, *Risk Analysis* 26(2): 347-351

<sup>32</sup> Selgelid, M (2009) Pandethics, *Public Health* 123: 255-259

<sup>33</sup> Department of Health (2007) *Pandemic Flu: A national framework for responding to an influenza pandemic*, available online at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_080734](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080734)

### ***Dealing with high-risk and vulnerable patients***

- 24 Given the scarcity outlined above, the most fundamental question that pandemic planning needs to answer is "who gets what if not everyone can get everything". Prioritization can serve multiple purposes, and these are often mutually exclusive. It has been shown that pandemic plans mention a number of competing goals that prioritization strategies may pursue.<sup>34</sup> These include:
- a) protection of high-risk patients
  - b) protection of key personnel in essential infrastructure and/or medical staff in order to maintain social functioning
  - c) protection of political decision-makers
  - d) protection of children and young people
- 25 This list illustrates two things. First, there seem to be different conceptions of what constitutes the highest priority in pandemic reaction policy. Secondly, many of the definitions of prioritized groups lack clarity. It is not obvious who is a high-risk patient, and in pandemics where information on the pathogen will only become available over time, such a classification may not be useful in the early stages of the outbreak, where insufficient data are available. Since pandemics of the same disease may affect different groups, as has been the case with influenza, there is no generic classification of who is particularly vulnerable and therefore more or less in need of receiving treatment.<sup>35</sup>
- 26 However, it has been suggested that beyond the clinical factors of a specific pandemic pathogen, socially vulnerable groups will be affected disproportionately during a pandemic, as they may lack access to health care resources or appropriate information. Consequently, it may be argued that pandemic planners should place particular emphasis on ensuring the existence of suitable communication strategies to inform all parts of society about the course of the pandemic.<sup>36</sup> This argument can be extended, in that pandemics represent a situation in which health care systems are put under particular strain and thereby exacerbate existing health inequities. While it will likely be neither feasible nor appropriate to remedy these inequities during a pandemic, planning for such an event may have to take into account that the burden of disease will not be distributed equally across society and that this will only partially be explicable by biomedical factors.

### **Ethics and Policy - Pandemic Response**

- 27 Pandemic preparedness can help to reduce the burden of disease in the case of an outbreak and formulate response strategies. However, some of the ethical problems that pandemics pose will only become more pronounced after an outbreak has occurred. Pandemics create conditions for health care systems which are in some sense unique.

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<sup>34</sup> Arras, J (2005) Rationing Vaccine During an Avian Influenza Pandemic – why it won't be easy *Yale Journal of Biology and Medicine* 78: 283-296

<sup>35</sup> Barry, J (2009) *The Great Influenza* (New York: Penguin)

<sup>36</sup> Lee C, Rogers W, Braunack-Meyer A (2008) Social Justice and Pandemic Influenza Planning: The Role of Communication Strategies, *Public Health Ethics* 1(3): 223-234

Unlike in the case of non-communicable diseases, communicable diseases make the patient both a victim and a vector.<sup>37</sup>

- 28 To some extent this is true for all communicable diseases; however the severity of pandemics and the far-reaching implications these may have for societies somewhat accentuate this dichotomy. Understanding the patient as a vector of disease may require that those who have not been infected are protected from the risks of transmission as far as this is possible. Under extreme conditions such as a pandemic, this conflict of interest is likely to result in the need to formulate a trade-off between individual rights and the common good.

### ***Individual rights, common good and obligations***

- 29 Many countries have legal tools in place which allow for the enforcement of isolation, quarantine or restriction of employment.<sup>38</sup> These are not limited to pandemic pathogens, yet they most commonly apply to those infectious diseases which are particularly contagious or pose the greatest health risks. As such, the corresponding legal instruments are highly relevant to the discussion of containment strategies. From an ethical perspective, the most challenging feature of such strategies is their sometimes far-reaching restriction of individual liberties. These may include enforced treatment, solitary confinement in the case of refusal to undergo treatment for certain diseases, or suspension of patient-doctor confidentiality.<sup>39</sup>
- 30 Whether or not such drastic measures are morally permissible may not only be a matter of principle. It will also depend on the expected risks involved in allowing patients to decide autonomously whether or not they wish to receive treatment or follow the instructions of medical experts. In the case of a pandemic with severe mortality and morbidity, it may be more acceptable to enforce compliance with evidence-based treatment protocols, than in less drastic scenarios.
- 31 Beyond the matter of trade-offs between individual rights and public good, pandemics also raise questions of obligations that society has towards those who are affected by efforts to combat the spread of a disease by compensating them for their losses. Compensation may either be appropriate after the event, for example in the case of enforced social distancing, e.g. by quarantine, where people are compensated for loss of income.<sup>40</sup> On the other hand, wherever measures of social distancing are voluntary or merely recommended, it may be necessary to ensure that people with lower incomes who cannot afford to take unpaid time off work, will be able to comply with the recommendations.
- 32 A second obligation which arises in the context of pandemic planning is an issue that is of general concern in infectious disease policy but is likely exacerbated under conditions

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<sup>37</sup> See Battin, M et al (2009) *The Patient as a victim and vector* (Oxford: OUP)

<sup>38</sup> Gainotti S, Moran N, Petrini C, Shickle S (2008) Ethical models underpinning response to threats to public health: A comparison of approaches to communicable disease control in Europe, *Bioethics* 22(9):466- 476

<sup>39</sup> *ibid.*

<sup>40</sup> Holm, S (2009) Should Persons Detained During Public Health Crises Receive Compensation?, *Bioethical Inquiry* 6:197-205

of a pandemic, namely whether or not people have a duty not to infect others around them, and what consequences arise from such a duty.<sup>41</sup> If people can be said to have a moral obligation not to infect others, there may be more substantial reasons to restrict the liberty of those who do not comply with acknowledged standards of reducing the risk of infection. However, a duty not to infect others may also be used to justify other liberty-restricting measures, such as a duty for health care workers who have direct patient contact to receive vaccination against infectious diseases wherever this is possible.<sup>42</sup>

### ***Rationing and Prioritization***

- 33 Health care systems can face extraordinary challenges during pandemics, leading to scarcity. This may be limited to specific aspects of health care, such as vaccine or antivirals, but during a prolonged and severe pandemic, it must be expected that demand exceeds supply for other health care resources, such as hospital beds, ventilators or drugs. It should be noted, that scarcity during pandemics need not be limited to health care resources – food, heating, fuel or essential infrastructure may equally be subjected to rationing in particular severe cases. However, for the purposes of this paper, particular emphasis will be placed on the prioritization and rationing of health care resources.
- 34 Many pandemic plans include specific references to prioritization orders that apply in cases of an outbreak - usually for vaccination against a pandemic pathogen.<sup>43</sup> Such prioritization orders differ significantly from a triage concept of prioritization that might be applicable after an outbreak and that will simply assign priority based on the severity of acute symptoms. Pandemic plans, as discussed above, are made under conditions of uncertainty. Thus, any predetermined order will have to make assumptions about who is at a particularly high risk during a pandemic and who therefore ought to be treated preferentially. In reality, such a definition of high-risk categories is much more difficult than may be initially assumed. While people with weak immune systems tend to be at greater risk, the 1918 influenza pandemic caused the highest mortality rates among healthy young men.<sup>44</sup> Whether or not such prioritization plans thus achieve what they are intended to do will depend on the accuracy of the assumptions about high-risk groups. The definition of inclusion and exclusion criteria for preferential treatment will have to be quite specific if they are to serve as unambiguous guidelines following the

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<sup>41</sup> Harris J, Holm S (1995) Is there a duty not to infect others? *BMJ* 311:1215-1217

<sup>42</sup> Van Delden J, Ashcroft R, Dawson A, Marckmann G, Upshur R, Verweij M (2008) The ethics of mandatory vaccination against influenza for health care workers, *Vaccine* 26: 5562-5566

<sup>43</sup> E.g. Ministry of Interior Health (2009), Interior Health Pandemic Influenza Preparedness Plan (Alberta, Canada) available online at <http://www.interiorhealth.ca/health-and-safety.aspx?id=468&terms=pandemic+plan> US Center of Disease Control, and Prevention (2008) Association of State and Territorial Health Officials (ASTHO), At-Risk Populations and Pandemic Influenza: Planning Guidance for State, Territorial, Tribal, and Local Health Departments (Arlington/VA), available online at: [http://www.diversitypreparedness.org/Topic/Subtopic/Record-Detail/18/audienceld\\_\\_15873/resourceld\\_\\_17147/](http://www.diversitypreparedness.org/Topic/Subtopic/Record-Detail/18/audienceld__15873/resourceld__17147/)

<sup>44</sup> Emanuel E, et al (2006) Who should get Influenza Vaccine when not all can?, *Science* 312 (2006), p. 854-855

outbreak of a pandemic. However, such a definition of criteria will potentially require a process of public deliberation if it is to meet with acceptance by those affected.<sup>45</sup>

### **Communication**

35 Given that pandemics have the potential to overwhelm existing health care structures and lead to demand outstripping available supply, public communication strategies may also wish to address the possibility of scarcity in the case of a pandemic, before such an event occurs. Beyond informing the public of the possibility of a need for rationing available resources such as vaccines, ventilators or ICU beds, policy makers may find it useful to involve the public into the decision-making process, as has been the case in a number of countries.<sup>46</sup> Such an involvement can aid decision-making in two ways. First, it may add to the information that policy makers have available by raising new questions or aspects of debate. Secondly, even where no new information is uncovered public involvement can add legitimacy to decision-making, by widening the group of participants to stakeholders who may have previously felt that their views were under-represented.

### **Special obligations of health care workers - and obligations towards them**

36 Pandemics may pose significant health risks, not only to patients but also to health care professionals who stand at risk of infection. During the 1918 influenza pandemic, many hospitals lost as many as half of their staff to the disease.<sup>47</sup> While it is generally expected that doctors accept some level of risk as part of their job, there is concern as to the point at which demands of health care professionals become supererogatory. In this case, the patient's right to treatment conflicts with the health care worker's right to life and health (and also potentially with the latter's contractual rights and obligations as an employee). This is of particular concern given the fact that health care workers not only have a right to their own health but may also have obligations to third parties, such as their own families and/or dependant. Unless health care workers are isolated from their usual environment throughout a pandemic, the determination of acceptable risks for health care workers will also have to take into account that by extension this risk will also be borne by relatives or household members.

37 Furthermore, health care workers may have particular duties towards their patients when it comes to minimising the risk of contagion. It has been argued that where vaccine is available, health care workers can be expected to be vaccinated so as not to act as vectors of a communicable disease in a health care or nursing environment where many people have compromised immune systems.<sup>48</sup>

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<sup>45</sup> Kass N, et al (2008) Ethics and Severe Pandemic Influenza: Maintaining Essential Functions Through a Fair and Considered Response, *Biosecurity and Bioterrorism: Biodefense Strategy, Practice and Science* 6(3): 227-236

<sup>46</sup> See e.g. Toronto Joint Centre for Bioethics (2005) *Stand on Guard for Thee: Ethical considerations in preparedness planning for pandemic influenza* (Toronto, Canada); Department of Health (2007) *The Ethical Framework for the Response to Pandemic Influenza*, available online at: [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_073179](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073179)

<sup>47</sup> Barry J (2009) *The Great Influenza* (New York: Penguin)

<sup>48</sup> Van Delden J, Ashcroft R, Dawson A, Marckmann G, Upshur R, Verweij M (2008) The ethics of mandatory vaccination against influenza for health care workers, *Vaccine* 26: 5562-5566

## ***Culling of Animals***

- 38 A disease with a pandemic potential is very likely to be a zoonosis, i.e. a disease which first affects animals and at some point adapts to human hosts. Even if it does not originate from animals, it is possible that it can infect animals as well as humans and hence establish an animal reservoir for itself. Hence controlling infected animal populations has an important role to play in preventing and containing pandemics. The most common measure in attempting to do so has been to cull infected animals and, more often, entire regional animal populations. The number of animals killed to protect humans may be significant. For instance, it has been estimated that between 2003 and November 2007, more than 100 million chickens were culled worldwide because they were infected (or suspected of being infected) with H5N1 avian flu.<sup>49</sup> While other methods have been tried and can work in certain circumstances – for instance vaccination – it is unlikely that culling can be completely avoided. Culling animal hosts of pathogens for public health purposes bring with it a series of ethical issues. The most obvious is whether and when killing animals to protect human health is permissible. Views at the extreme ends of the spectrum asserting, on the one hand, that it is never permissible to cull or, on the other, that it is not at all problematic to do so, are unlikely to appear very convincing. If the widespread killing of animals needs some justification, then a level of risk for humans that justifies culling needs to be specified. However, setting general criteria or principles seems a difficult task, for it is unlikely that animals can be treated as a single general category and that the same justification is needed to kill lice, rats and dogs. Biases in human sympathy and emotional reactions towards different animals further complicate the matter.
- 39 Even apart from animal rights and welfare concerns, the culling of animals raise important ethical questions. In the case of farmed animals some compensation seems fair and practically necessary to secure cooperation from farmers. On the other hand, unhygienic and inappropriate farming practices may at times play a role in favouring genetic recombination of pathogens and in promoting the fast spread of them. The promotion of more hygienic farming practices may go against strong economic interests or even against the need to feed growing populations. In the case of wild animals, the culling may have serious ecological consequences that need to be investigated, and again some criteria for weighing them against public health imperatives are needed.

### **Questions the Nuffield Council might like to consider**

- How should we prepare for future pandemic events, if we cannot know when they are likely to occur and how dangerous they will be? What role does epidemiologic modelling play in this context?
- Which principles should inspire international cooperation in surveillance and response? How far should reciprocity go? Is it desirable and realistic to aspire to an international redistribution of resources to control pandemics?

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<sup>49</sup> Malani A, Boni MF & Galvani AP (2008) Avian Flu and the Procurement of Chickens for Culling, unpublished paper <http://ele.arizona.edu/files/ELEmalani2-8-08.pdf>; cf. Enemark C (2006) Pending Pandemic *Australian Journal of International Affairs* 60(1): 43-9



- What role should pandemic preparedness play in future health care expenditure? For example, how much money should be spent on pandemic preparedness e.g. in the form of surveillance, preparedness exercises or the stockpiling of medical resources for potential catastrophic events?
- Can preparedness be reasonably broadened to include diseases other than pandemic influenza?
- How will the concept of preparedness have to change over time, given the demographic changes as well as the expected further growth of international travel?
- What rights to protection do health care workers have during a pandemic – and how may these be reconciled with their professional duty to help the patient?
- Do certain professional groups, e.g. health care workers or carers for elderly or vulnerable patients, have a moral obligation to be vaccinated in order to limit the danger they pose to their patients as an agent of infectious disease?
- Can the need for good surveillance data be reconciled with patients' rights to privacy?
- What restrictions of individual liberty are acceptable in the interest of society?
- Should individuals whose liberty is restricted as part of pandemic containment strategies be compensated, and if so how?
- How do we decide on appropriate and fair rationing and prioritization strategies for resources that are expected to be scarce during a pandemic?
- Is there a way to secure honest information and reasoned involvement of the public in pandemic response?
- How flexible ought pandemic plans be in order to take into account public reactions and/or new evidence regarding the disease and its spread?
- When and how is the mass culling of animals to avert pandemics justified?