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Human Rights, Stigmatization and Risk of Discrimination Against Specific Population Segments and Target Groups

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EXECUTIVE SUMMARY

Stigmatisation is an ancient concept, one that humans as a species may have evolved as a social behaviour under certain circumstances. Modern academic study of the concept began in the second half of the twentieth century with the seminal work of *Goffman*. In the decades since, sociologists and psychologists have attempted to refine the conceptual underpinning and definition of stigmatisation in order to take into account of phenomena that have been observed in different circumstances. In the contexts of epidemics, important aspects to take into account include that stigmatisation often involves individuals with readily identifiable traits (such as individuals belonging to minorities), that such traits can often be linked to characteristics that are given negative moral connotations and that individuals most susceptible to stigma are those who occupy inferior positions in relationships of power. In the context of epidemics, groups that are prone to stigmatisation include those groups that have a perceived connection with the geographic origin of the outbreak in question, members of the medical profession, those who are part of pre-stigmatised groups, those who have connections to perceived animal origins of an outbreak and those individuals who actually become infected themselves. Past experience, especially the recent outbreaks of SARS, H5N1 and H1N1 have shown these groups to be vulnerable to problems associated with stigmatisation.

Those vested with responsibility for planning public health responses to epidemic situations should take into account the existence of such individuals and their susceptibility to stigmatisation when planning their actions. Such activities include the provision of public health information, testing facilities, treatment and even vaccination. Stigmatisation should be avoided not only because of the moral issues that may be involved, but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. These include the possibility of healthcare avoidance behaviours, something which can have very serious consequences during an epidemic and is capable of worsening its course. Such issues have for example considerably worsened the course of the HIV pandemic. As has also been observed amongst various stigmatised groups, stigmatisation can also result in a decreased motivation to seek the goods required to prosper in life. Stigmatisation caused during the public health response to an epidemic is therefore capable of creating negative affects that last long after the epidemic in question has subsided. These include not only a lesser motivation to seek healthcare, but also in areas such as education and employment. Stigmatisation can also have a negative effect on the ability of such individuals to obtain such goods on an even basis with other member of society and thus reduce the quality (and even longevity) of affected individuals' lives. In addition, long-term stigmatisation is capable of producing serious direct effects on the health of individuals in the form of worsened cardiovascular health. One important aspect that has been identified with regards to stigmatisation is that it can occur even where there is no actual discrimination occurring. Stigmatisation can arise through human perception unaided by state or official organs. Planners of public health responses should be on guard for such possibilities and seek where possible to avoid them. Modern social media technologies will provide an important opportunity for such authorities to monitor such perceptions and intervene if needed by the timely provision of accurate information. Given the serious nature of these negative effects the planners of public health responses to epidemics should seek to, where possible, avoid or at least minimise, creating new problems of this type or entrenching those that pre-exist amongst groups that are already stigmatised. Failure to do so may result in not only negative consequences during an epidemic but also after the epidemic in question has disappeared.

Stigmatisation should be avoided not only because of the negative aspects described above but also because of its corrosive affect on a society's plurality and therefore its democratic character. In order to avoid unnecessary stigmatisation, there are two principal strategies available to those who plan public health responses. The first is to ensure that the provision of healthcare services is made on an equal basis to all, irrelevant of society's opinion on their moral status. This can be achieved primarily through legislative methods ensuring that such equal treatment is enshrined in law. This acts to prevent vertical discrimination by the state against those who are stigmatised, by avoiding that such individuals are left out of the provision of key medical services during an epidemic. However as has been described briefly above, the active act of discrimination does not need to be present in order for stigmatisation and its negative effects to occur. One key act of discrimination is a sense of self-loathing that can result from the perceived negative perceptions of one's peers' views on their own existence. Such negative perceptions can establish themselves even in the absence of any overt discrimination by the state or other actors in society. In order to reduce such a sense of self-loathing it will be necessary, during the context of epidemics, for public health authorities to engage with groups or associations that represent those who are stigmatised in society. This will allow public health campaigns to take into consideration the sensitivity of such groups and also allow stigmatised groups to reinforce their own sense of self worth, allowing them to resist the stigmatising pressures from other members of society. Such an approach has shown itself to be very efficacious in the reduction of stigmatisation for those individuals who are HIV positive. The engagement of such groups could be optimisednot only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue in the planning of a response to a potential epidemic.

Human rights have a valuable role to play in the regulation of responses to epidemic situations. Human rights systems have been rising in prominence in recent decades and have begun to challenge the traditional role of medical ethics as the dominant system for deciding upon the provision of care in many settings. The ability of human rights systems to help balance competing claims by various rights holders upon limited resources makes them suitable in assessing public health strategies in the contexts of an epidemic. States are obliged through both international law and their own national law to respect a variety of human rights principals. At the international level whilst the state may be bound to respecting each treaty, the availability of a reliable enforcement mechanism may depend upon the treaty in question. This can be seen immediately by comparing the lack of an enforcement mechanism available under the International Covenant on Economic and Social Rights, (the ICESR) (and to a certain extent the International Covenant on Civil and Political Rights (the ICCPR)) with the potent mechanism available under the regional European Convention on Human Rights(the ECHR). It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality. The Human Rights Principals that are applicable during epidemic situations vary, from very precise duties upon states to act to prevent and deal with epidemics, to other more general principals that will inevitably apply in such contexts. These include principals associated with both civil and political rights and also social and economic rights. Important principles to consider are *inter alia* the right to life, the right to health, freedom from inhuman or degrading treatment, rights of physical freedom, the right to a private and family life and also freedoms against discrimination.

The Right to Life concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war). Whilst there is some case law in some states that interprets the right to life as providing a positive duty upon states to provide healthcare this is limited, with most interpretations, including the ECHR foreseeing a limited role for the right for life in providing for a positive duty upon states to provide healthcare facilities.

A positive duty to provide healthcare finds for itself a more natural home within **the right to health**, located in various international treaties. This social end economic right foresees a duty upon states to provide healthcare for individuals in need of such services. This right has been used by various groups of individuals, most notably in the developing world, to secure access to vital healthcare services such as vaccinations or antiretroviral therapy. The use of such a right comes with several caveats however. Most notable is the relative nature of such a right – it provides not an absolute duty to provide a certain level of healthcare, but a duty to move in the right direction as much as available resources permit. Another problem is the discretion given to the state (especially in the west) to make its own value judgements where competing claims occur upon resources. The social and economic nature of the right also weakens its effectiveness given that its enforceability under international treaties is usually limited (though some states do actually have an equivalent principal written into their national law). It is therefore not likely that individuals will be able to make use of the right to health (unless it is a constitutional principle in their state's constitution) to compel states to make vaccinations, testing and treatments available where the state, has in the context of an epidemic, deemed such treatments not to be cost effective or an efficient use of available resources. This is important, as many states, in their preparedness plans for a serious epidemic, will envisage targeting certain valuable or vulnerable groups for vaccination. Indeed it may even be impossible for public health authorities to provide treatment, such as vaccinations, to anyone who might want such an intervention as the availability of such treatments may be limited (or not even exist) at the time an epidemic strikes. It would be advisable however for a state to base such prioritisation on objective and clearly demonstrable grounds so that it can be shown that such prioritisation is in line with its obligation under the notion of a right to health under international law.

The **freedom from inhuman and degrading treatment** provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice the right has been closely linked to the concept of informed consent. This concept, which arose in the decades following the Second World War requires such consent to be present before treatment can be carried out upon individuals. This notion however does not sit easily with the potential use of several draconian procedures in the context of a pandemic. These include quarantine, compulsory testing, compulsory treatment and also compulsory vaccination. Such powers are recognised at national level by many states in their national law and also at international level in *inter alia* the International Health Regulations. Case law under the ECHR has however indicated that such treatments are not necessarily precluded. The case of *Herczegfalvy* demonstrated that states may carry out treatments on individuals without their consent if such individuals do not have the capacity to consent and the treatment in question is indeed a medical necessity. The *Nevmerzhitsky* case even permitted the compulsory treatment of a prisoner who did possess the capacity to consent and had refused the treatment in question. Despite this surprisingly permissive ruling the court did indicate that states must demonstrate there are no other less stringent courses of action available. It has been suggested however that the future may herald changes in the way the European Court of Human rights views this matter. The notion of informed consent is becoming ever more deeply imbedded and the idea that individuals can be subjected to treatments without their consent is certainly at odds with this. Given this, it could be viewed as possible that future cases brought before the EtCHR may view this matter differently. Public health authorities should therefore be cautious in relying upon the use of compulsory treatment measures, being able, where they do, to clearly demonstrate that other, less severe, courses of action were not available.

Engagement with **the right to liberty and security of person** is also a significant possibility during a serious epidemic. The right envisages freedom for individuals from arbitrary detention. There is obvious scope for conflict with such a right with techniques such as quarantine which have been employed for many years during serious epidemics. This right was considered extensively by the EtCHR in the context of public health powers in the case of *Enhorn*. In that case the court ruled that the detention of individuals under public health powers may be permissible but only if certain strict conditions are met. Firstly such detention must be necessary and proportional, meaning that the detention or quarantine must actually serve a purpose and must be the least severe method available in order to achieve that purpose. In addition the court highlighted that in order for such power to be valid they must already exist within legislation and be outlined in sufficient detail that their potential use be foreseeable. These will represent important requirements the planners of public health responses to epidemics. If the potential use of such powers is envisaged it will be important in the context of legal preparedness to ensure that powers already exist in legislation before an epidemic arises. This may entail a review of pre-existing powers and their alteration as may be necessary. International or regional organisations such as the UN or the EU may also have a role in ensuring that their constituent members have updated their legislation as may be necessary and informing them if this is not the case. In addition, those tasked with implementing potential quarantine measures during epidemic situations should be prepared to be able to justify both the necessity and proportionality of the actions should the need arise through legal challenge.

The **right to a private and family life** will also represent an important concept for public health planners to consider. In the context of healthcare, it has been linked to both positive and negative obligations. In terms of positive obligations, a state can be required to act where such action is likely to protect an individuals private or family life. Negative duties envisage however an obligation upon states to desist from acts that may prevent individuals from realising this aim. Like the right to liberty and security of person this right is usually not perceived of as an absolute right. It can be engaged by states in order to secure the protection of public health, but only where, once again, the use of the methods in question meet the concepts of necessity and proportionality. Given the wide ranging embrace of this right it can have implications in a variety of ways for those tasked with planning public health responses to an epidemics. With regards to positive obligations in terms of the provision of medical services the court has stated that whilst this right could be used to give voice to complaints regarding public funding and treatment procedures, it is the states themselves that are often in the best position to decide how best to achieve the balance between the various competing needs for healthcare that exist within a society. A more important role for this right is likely in the area of confidentiality of individual data during a medical emergency. The EtCHR has also clearly linked the concept of data protection to that of privacy and of being important to the enjoyment of a private and family life. In Europe the responsible regime for the protection of personal data is the data protection framework. This regime also governs medical data where such data is classified as being sensitive in nature and therefore attracts the highest level of protection. The data protection regime provides important requirements which public health planners should consider. Such requirements may be respected in several ways. One is the use of anonymised data. Another possible method is relying upon the data subject to give their express consent for the use of non-anomynised data. However, the use of non-anomonous data may be required in the context of an epidemic, especially in the initial stages where there may be a need to gather data on the properties of a novel infectious agent. Such data may be processed without individual consent if doing so would be in the public interest. This however requires that legislation governing such processing is in place before hand. In *Z v Finland* the court outlined that only in certain instances where it is clearly in the public interest can such details be revealed without individual consent. Adequate preparation will be important for states in ensuring that they are compliant with data protection requirements and their wider duties to protect the private and family lives of individuals. In terms of data protection this will involve anonymising all personal data where possible. Where this is not possible it will be important to have pre-drafted legislation in place allowing for such processing in the public interest. This is a process that will obviously need to be in place before an epidemic takes place. Such legislation will have to be sufficiently precise to comply with the legal requirement of foreseeability but also to allow sufficient flexibility to deal with future unknown and unexpected pandemics.

The **right to non-discrimination** is not a stand alone right. Rather it can only be engaged in conjunction with another right. This means that in order to use this right, individuals must be presented with a situation that engages another right (e.g. the freedom of private and family life or the right of liberty and security of person). If such a situation presents itself individuals can not be denied their rights under the convention because they belong to one of the groups in question. This right of non discrimination applied to a range of groups such as race, ethnicity and religion and, as has been more recently accepted to those who have a different health status (e.g. those who are HIV positive). Discrimination occurs where members of one of these groups are treated differently from other persons in an analogous situation without an objective and reasonable justification. This can provide an important protection for individuals who suffer from health conditions in ensuring that they are not unnecessarily discriminated against. In the context of public health provision this could include the withholding of treatment from certain groups because of safety or efficacy concerns. This right could also be used by individuals who that are denied access to other (non-healthcare related) public services because of their health status. This could conceivably occur where individuals have become (or have been) infected during a pandemic. If states take action which *prima facie* discriminates against individuals because of the health status, they must demonstrate that such action was, once again, both necessary and proportional. The more vulnerable the group in question to discrimination is, the more onerous the obligation upon the state to show that it acted properly.

Human Rights Instruments instrument provide important protection against discrimination for vulnerable and stigmatised groups. Stigmatisation can however, by its very nature, result in various negative effects, even where stigmatised individuals are not the result of direct discrimination. This can be through indirect structural discrimination for example that is often difficult to prevent, through health care avoidance by those that are stigmatised, through the negative health effects of long term stress, through perceived physician bias and even through a reduced motivation to strive for the necessary goods of a successful life. There is some doubt as to whether human rights instruments have the ability to prevent such a situation from arising in the first place. Human Rights instruments do not seem to be engineered to provide the same protection against stigmatisation as they do for the protection of individual rights and for protection against discrimination. This problem was highlighted in the recent ECHR case of *Kiyutin,* where the court declared that the "full realisation' of human rights principles would reduce stigma, allowing benefits in terms of prevention and treatment. In order to ensure this, states should ensure *inter alia* access to 'education, in heritance, employment, healthcare, social and health services." Thiscase provides an interesting insight into how the European Court of Rights views the relationship between stigmatization issues and human rights. Whilst not attempting to specify what exactly stigmatization is, the court made it clear that stigmatization is something that should be avoided for individuals that have health issues such as HIV. The court was of the opinion that the protection of human rights and individual freedoms was essential in order to prevent stigmatization of those with such conditions. This can be seen as taking a very different approach from academics who have found that stigmatization can give rise to discrimination but does not have to do so. Such a view sees discrimination as something that usually flows from stigmatization and not necessarily the other way around. Thus discrimination can occur of stigmatized individuals, but stigmatization can occur without discrimination and even when discrimination is prima facie prevented. There seems therefore to be a 'chicken and egg' style difference in the way in which the EtCHR and academics such as Link and Phelan view the conceptual relationship between stigmatization and discrimination. The court's judgment also made no reference to the various negative effects that occur to stigmatized individuals even if there is no discrimination against them. Given this, one might take issue with the courts assessment that the protection of individual rights and fundamental freedoms is sufficient in itself to fully prevent the negative effects that are associated with stigmatization. This is because it is possible to have negative effects from stigmatization even where no discrimination is occurring with regards to the protection of individual and fundamental rights of individuals by states.

Whilst there may thus be some scope under the ECHR to guard against potential stigmatization as a result of public health campaigns during an epidemic, this may however in reality be limited by several factors. Firstly it will likely be necessary to demonstrate such stigmatization will result in a right under the ECHR being breached. Additionally it will need to be shown than the measures taken that resulted in such breaches were not necessary and proportionate to the aims of the measure in question. Where as is often the case in public health campaigns, the aim is to prevent mortality or serious morbidity, it is likely that in most cases the stigmatization that occurred as result would not be deemed sufficient to render the measures taken disproportionate. In addition, given that the provision of information is at the least interventionist end of a long possible list of potential medical interventions it is not likely that such measures would not be seen as necessary. This is immediately obvious when one considers other alternatives such as quarantine, compulsory vaccination, and compulsory testing or travel control measures. It is therefore not likely that in most cases another less severe course of action could be found for the provision of medical information. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

Introduction

This document aims to highlight key issues concerning stigmatisation and human rights in the context of epidemics. The aim is to provide a well rounded state of play of the salient issues in these areas. The first section of this document will introduce the reader to the concept of stigmatisation. This will begin with a description of the classic conception of stigmatisation and then explain some of the refinements that have been made in recent times to the conceptual basis of stigmatisation. The focus in this section will be on concepts that are relevant to potential issues in epidemic situations. The second section will outline the negative effects that can occur when stigmatisation exists both in direct and indirect terms. The aim here is to outline why it is important that stigmatisation is avoided as much as is possible. The third section then proceeds to look at examples of stigmatisation that have actually been documented in epidemic situations. This will inter alia look at stigmatisation that occurs as a result of an infectious agent's perceived geographic origin, as result of being part of the medical profession, to individuals that actually become infected and to individuals that are part of pre-stigmatised groups. The following section will then proceed to look at methods that can be utilised in order to avoid possible stigmatisation in future epidemics. The fifth section will then analyse the suitability of human rights as a system to regulate public health responses to epidemics and make a comparison with the use of medical ethics for such purposes. The sixth section will aim to outline the various human rights principles that can be engaged in epidemic situations. The final part of this document will represent a discussion of whether human rights systems provide sufficient protection against the possibility of stigmatisation in epidemic situations.

1. An Introduction to the Concept of Stigma

The first section of this document will consist of a mainly theoretical discussion of the concept stigma. This will involve an analysis of its origin as a term used in everyday discussion and then a focus on the developments that have occurred in terms of academic study in the area in the recent times. The aim will be to describe the complexities of the concept to the reader. An understanding of these issues will allow the reader to be aware of certain characteristic that make individuals more vulnerable to stigmatisation than other individuals.

1.1 The Concept of Stigma Throughout the Ages

Stigma is a term that is heard frequently in every day parlance. The term has been used since ancient Greek times[1] (Jones, 1987) where one would speak of a person possessing a *stigma* if they possessed a mark or sign that indicated the individual was of inferior moral quality, a lesser being so as to say, than the average person. A stigma could indicate for example that someone was a slave or that they had committed crimes. Stigmas might be applied by way of branding, so as to mark the individual so that individuals that might encounter him or her would know his or her true moral status and so that one would not mistake him for a normal individual. Whilst Christianity imbued *Stigma* with another meaning for some time (Ruard

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[1] Penal tattoing, whether applied to delinquent slaves to criminals or to prinsoners of war was brorrowed by the Greeks from Persian culture. The Romans later adopted the practice and it was thus extended throughout the empire.

Ganzevoort, 2008)(related to the virtuous wounds of Christ), modern day use of the word seems to have returned to something similar to the original connotation . In the academic world, the notion of stigma began to attract significant attention in the 1960s. In his seminal work (Hsin Yang et al, 2007)*Stigma – Notes on a Spoiled Identity*, Goffman attempted to outline exactly what stigmatisation involved. To him it involved a process whereby 'normal' individuals discerned or might be able to discern that the stigmatised individual possessed traits that made him different than 'normal individuals'. Rather than symbols of 'prestige', such as expensive clothing or accessories, which are capable of marking out individuals of 'superior' quality, stigma symbols indicated that the person bearing them was of a lesser moral quality than members of the social class he might otherwise seem to belong to. Such symbols could therefore be used to identify individuals as not belonging to the normal social class of persons. Such individuals would merit a higher level of concern than individuals considered normal. Individuals suspected to be carrying infectious disease would be one such category of individuals.

1.2 The Ideas of Goffman -The Discredited and the Discreditable

According to Goffman those with stigma can form two groups that experience stigma in different ways, the *discredited* and the *discreditable* (Goffman, 1963). For the discredited, the external signs of his or her stigma are strong and unavoidable. Such individuals can be immediately identified as not belonging to the 'normal' class of individuals. Examples of such stigmas might be missing limbs or scarring. In the context of an epidemic it may be individuals with unmistakeable symptoms of infection.Another example may be individuals from an ethnic minority suspected of being at a higher risk of carrying the infection may be another example. The discredited as Goffman described usually have a trait that "can obtrude itself upon the attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have upon him". Thus, according to *Goffman,* others will regard an intelligent individual with a bodily disfigurement primarily as a disfigured individual, not as an intelligent individual.

Other stigmas however are not so obvious to strangers. They may only reveal themselves after the stigmatised individual reveals certain information or after a normal individual discovers something about the stigmatised individual. Goffman gave such individuals the term of discreditable. (Joachim, 2000). Such individuals would be discreditable and strangers meeting them would not know of his difference immediately, rather it would only become apparent after the individual concerned did something to reveal his stigma or decided to release information regarding it in some other way. Individuals that are HIV positive are one example. This could occur for example when an individual suffering from a condition decides to self-administer medication in public using a syringe. Once this occurs the individual concerned would move from being a *discreditable* individual to a *discredited* one.

Discredited and discreditable individuals face different pressures in dealing with their stigma. Both are important within the context of an epidemic. The discreditable live under the fear of having their stigma revealed to others. A discreditable individual will seek to avoid becoming a discredited individual. Their thoughts and actions can be preoccupied with hiding evidence of their stigma as much as is possible. This can cause anxiety and stress to the individual who may not feel able to act himself. (Link & Phelan, 2006) It can also result in healthcare avoidance strategies whereby a sufferer of a condition does not seek medical treatment in order to keep his condition hidden[2]. If a discreditable person is in control of information

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[2] This is a well known problem for individuals that suffer from HIV. See page 17 for a fuller explanation.

pertaining to his disease he can choose two options. The first, if he or she feels that such actions would be well received in the environment in question, would be to reveal details of his condition. The second, if he or she is not so confident of a good reception would be do what *Goffman* termed as '*passing*'. Passing involves attempting to pass oneself off as a 'normal individual' because one fears the consequences of revealing their true identity. Whilst this might seem disingenuous to an individual who does not possess the stigma in question, the importance of being able to decide whether or not to 'pass' for a discreditable individual should not be underestimated. (Joachim, 2000).

Discredited individuals however face a different array of negative emotions. These individuals face immediate recognition upon contact with normal individuals. Thus rejection or the differential treatment of these individuals can be immediate. Discredited individuals often therefore feel the need to avoid contact with normal individuals in order to avoid the negative aspects that such interaction can bring about (Goffman, 1963). Discredited individuals are likely to feel that their privacy is invaded by mere interaction with normal individuals, as their different status is apparent to other individuals immediately. The discreditable individual on the other hand may feel more comfortable if they are able to carefully manage information pertaining to their status and maintain their ability to keep their status hidden if needs be. For the discreditable individual the ability to carefully manage information regarding their status is important, it allows them to make an informed decision about when and where to disclose information relating to their stigma to other individuals based upon their perception of how such information would be received (Joachim, 2000). Those involved in responding to an outbreak of medical disease must take into account these aspects in order to maximise the response to the outbreak and reduce where possible healthcare avoidance.

1.3 Refinement and Development of the Concept of Stigmatisation

There has, in the decades following Goffman's work, been an enormous expansion in the research conducted on issues of stigmatisation, both in terms of conceptual discussion and also empirical investigation (Link & Phelan 2001). This has led to elaborations, conceptual refinements and importantly also to repeated demonstrations of the possible negative aspect stigmatisation can have on individual lives. This development has allowed the concept of stigmatisation to be applied to numerous circumstances, including the provision of healthcare and also medical responses to outbreaks of infectious disease. One aspect of contemporaneous treatment of stigmatisation issues that can be attributed to the shear breadth of the field as it now stands, is that the subsequent development and nuancing of Goffman's work means that there is no one universal definition of what exactly constitutes stigmatisation. On the contrary, there are many different definitions of what exactly constitutes stigmatisation. One problem with this is that the voluminous quantity of research on stigmatisation issues that exist can be based of a variety of different definitions, with some based on Goffman's original concept of a discrediting attribute, others using more recently and more refined concepts and still others that simply use the common dictionary definition of stigmatisation. The following section of this document will explain some of these refinements in the concept of stigmatisation. A comprehensive review of the entire body of work on stigmatisation is however outside the scope of this work. As a result an emphasis will be placed upon aspects that are pertinent to problems of stigmatisation associated with infectious diseases.

1.4 Stigma in The Contexts of Relations of Power

One recent innovation has been to refine the concept of stigmatisation to take into account the importance of the internal element involved, namely a feeling of self loathing (Link and Phelan 2001). This proposed framework not only does stigmatisation in various contexts refer to an and undesirable trait but also encourages a sense of self loathing with results in the individual concerned devaluing themselves. This makes it more likely that the individual concerned will take steps to hide the trait in question. This conception is useful because it can help explain many negative aspects in terms of individual outcomes that have been linked to stigmatisation, especially concerning health related outcomes. When an individual is stigmatised the aim is not only that a negative trait is identified and linked to individuals or groups but also a processes that causes the person with the identified trait to perceive it as undesirable. This perception of a person's own negative trait will often result in the individual concerned taking steps to hide the trait from others. This represents a thought process whereby the stigmatising party judges not only that it is undesirable to possess a certain trait but also that the individual involved should judge it undesirable also. There are several important factors that are required in order for stigmatisation to occur. Each of these has a relevance for public health authorities. These are described below.

__The need for a differentiating Trait__ - In order for stigmatisation to occur individuals must be in possession of a trait that can be used to differentiate them from other members of the population. Furthermore such a trait must be socially relevant. [3] This will therefore include for example traits that individuals use to differentiate each other on a social basis. These can include for example age, gender and racial profile. These groups often represent gross simplifications by individuals who perceive themselves as not being part of the group and can therefore include individuals who do not wish to be perceived as part of the group in question.[4] A bisexual person for example may often be classed as gay by straight people despite the fact he would not categorise him self as such or an individual that is of mixed race origin may be categorised as black by white people despite not feeling that they belong in that category. In the context of an outbreak of infectious disease individuals who, because of a cultural link to the geographic place of origin of an infectious disease or other individuals who because of certain lifestyle behaviours may be more susceptible to infection are ready examples of individuals that are capable of easy identification.

__The Linking of Differentiating Traits with Negative Attributes__. -Goffman recognised that individuals with identifying traits would often be linked to negative assumptions that rather than based on the behaviour of the individual concerned would be based upon assumptions or stereotypes. The stereotype in which the person has been linked to may be based upon an assumption that the trait holder possess a number of negative or dangerous properties (Link & Phelan 2001). Individuals who have a history of mental illness may for example be perceived as being dangerous or medeterainian individuals may be perceived by north Europeans as being work-shy without any knowledge of the individual concerned but based on the popular stereotype. In the context of an infectious disease for example, individuals that form part of an immigrant community in one country may become associated with a risk of infection from an infectious disease that arose in the country of origin. This may be the case for example even where individuals have not returned to their 'country of origin' for years and are likely pose no greater risk than members of the general population.

3This would preclude such examples as one's social security number and the (normally the shape of one's ears.

4 Vietnamese people were for example assumed to be of Chinese ethnic origin in the SARS outbreak in Canada. This phenomenon will be described in more detail later. See page 21

The Separation of Labelled Individuals from Mainstream Society- Individuals that possess the trait in question should be part of a group that is capable of being set apart from main stream society. This usually means that those possessing the trait in question are part of a minority that can be conceptually separated from others. Immigrant groups or homosexual groups provide obvious example of such group. Elderly individuals can also be form such a group. Individuals in these groups are capable of being separated conceptually easily from mainstream society i.e. indigenous or straight individuals. This process involves a certain level of dehumanisation where individuals become the thing they are labelled with (Estroff, 1989). This would mean for example individuals infected with a infectious disease becoming considered merely as 'infected' and no longer as human beings.

Status Loss in Social Hierarchy – Stigmatisation has the effect that individuals that have been linked to negative stereotypes experience a reduced perception of their perceived social ranking (Link & Phelan, 2001). It has been shown that unacquainted individuals if placed within a group are more likely to orientate themselves so as to place individuals that are linked to negative stereotypes in a lower position of the social hierarchy of that group (Driksel & Mullen, 1990). Research has for instance as shown that properties such as race and gender influences the position people are assigned in the hierarchy of such groups. The fact that individuals who have traits that can so easily lead to devaluation and a lower position in social hierarchies can lead to very real disadvantages for such individuals in day to day life. One can easily envisage the disadvantage this problem entails for stigmatised individuals at work, in school, in applying for places at university's and so on. During an outbreak of infectious disease, the extra stigmatisation that might occur to already stigmatised groups such as immigrants and even homeless people can become even stronger.[5]

The Existence of Imbalances in Power Relationships – Where stigmatisation occurs there usually exists an imbalance in power relations between individuals in society. It is where such relationships exist that the negative perceptions (or even the perceived negative perceptions) can give rise to negative consequence for individuals (Link & Phelan 2001). This is primarily for two reasons. The first is that individuals with more power have the ability to effect the lives of those without power in negative ways. They can for instance choose not to employ negatively stereotyped individuals or not allow them to send their children to the school that they desire. In such instances stigmatised individuals can be subjected to discrimination by individuals that have more power than they do in their social relationships. The second way in which individuals can suffer from discrimination can occur even in fairer societies were such discrimination is not permitted and equal treatment is mandated. This is because stigmatised individuals, aware that they are perceived to have a lower social status than other groups are likely to behave differently as a result in their relationships with non stigmatised individuals in positions of power[6]. For instance a stigmatised individual may be less demanding with his doctor than a non stigmatised individual would be. This results from the sense of self-loathing that stigmatisation can bring about. This self-loathing manifests itself in a lower sense ofself worth and an expectation of poorer treatment by those in positions of power. This concept is described in more detail below.

Discrimination is not necessary for a negative outcome to result from stigmatisation

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[5] Pre-stigmatised groups are more likely than other members of the population to suffer stigmatisation during an outbreak of infectious disease. See page 23

[6] See the following for a description of the ways in which stigmatisation can be harmful even when there is no discrimination present.

One can discriminate against individuals by treating them differently than others for example by denying them the same access to healthcare or schooling. Where such decisions are not based on the objective merits of individuals but on subjective judgments linked to negative stereotypes that arise through stigmatisation discrimination occurs. One damaging effect of stigmatisation however is that it results in not only other individuals in society, but also the stigmatised individuals themselves, viewing themselves as inferior to non stigmatised individuals (Link & Phelan 2001). It has even been contended that this is a hallmark of stigmatisation in general - the intention of stigmatising parties to make individuals judge themselves in a negative light, resulting in a sense of self loathing (Courtwright, 2009). In this way stigmatisation can be separated conceptually from discrimination. Where discrimination occurs the discriminating party views the discriminated party in a negative light and treats that person unfairly. The discriminating party may for example have no intention of inducing that individual to perceive themselves in a negative manner, they may not even care about such an outcome. A good example of this is where a potential employer refuses to employ someone because of the racial origin but hides from the individual concerned that this was the reason for his decision. Where the intention is to stigmatise however, the stigmatising individual intends to bring about a situation where the individual or group concerned views themselves in a negative manner. In this situation the stigmatising individual may not be intending to deny the individual something he wants or needs and therefore is not acting to discriminate as in the first example. A good example of such an event would be where an individual castigates a homosexual in the street for being promiscuous or immoral, causing that person to feel that he should hide his sexual orientation from others in the future.

Given that numerous negative effects can be attributed to stigmatisation (especially in the healthcare context) an understanding of the difference between stigmatisation and discrimination is important.Discrimination can occur a result of stigmatisation or stigmatisation can be reinforced by discrimination. Crucially however stigmatisation can exist in situations where discrimination is prima facia not possible. This means even in situations where in modern democracies discrimination is forbidden, stigmatisation can still be present. Stigmatisation can result in negative outcomes for both stigmatised individuals and society in general, even where discrimination is not permitted. This is because, as has been identified above individuals who are stigmatised often have a negative image of themselves which can result in detrimental behaviours that can produce negative outcomes in a variety of contexts including healthcare. It is therefore important to be aware that the elimination of the possibility of discrimination by societal structures is not sufficient to ensure that stigmatisation does not occur. Stigmatisation can present a host of problems that produce negative outcomes even if discriminatory acts are per se forbidden. This is why it is important that there is an awareness of potential stigmatisation issues in epidemic contexts if undesirable outcomes are to be avoided An understanding of this conceptual difference also helps in understanding why human rights based solutions can not be relied upon to avoid all negative aspects associated with stigmatisation that might arise as a result of human health campaigns as a response to infectious disease. The potential negative outcomes that can occur as a result of stigmatisation will be explored in the following section. Those associated with more active forms of discrimination will be described later in the document in the section concerned with human rights.

2. Negative Effects of Stigmatisation

Stigmatisation can create and exacerbate healthcare inequalities. This is because stigmatised individuals can often act differently in terms of their behaviour in seeking healthcare than others. This can flow from the negative self-judgments such individuals have made as a result of their stigmatisation. Such negative judgments can result in a sense of shame that increases the likelihood that individuals will opt not to seek help in order not to expose themselves to others (Courtwright, 2009).[7] Such a reaction for example can result from the expected social reaction that is likely to result from a particular diagnosis (e.g. HIV, hepatitis etc.) Under such conditions those that are stigmatised often feel a need to hide their conditions from not only the public but also health care professionals. In addition, during the context of an epidemic marginalised groups (HIV again being a prominent example) that are already the source of stigmatisation, may often be more at risk of contracting the condition in question. This can lead to a vicious cycle whereby the stigmatisation that such groups feel is reinforced by both the epidemic in question and the healthcare response to it. Stigmatisation in such instances can therefore lead to a worsening of pre-existing healthcare inequalities. This effect of stigmatisation means that even a society that envisages the classical universal provision of healthcare may have varying results for various sub groups of the population. Stigmatisation is capable through differing mechanisms of bringing about negative outcomes for affected groups. Such negative outcomes can be classified into both direct and indirect effects that will be examined below.

2.1 Direct Effects on Health – Stress Responses

There is evidence to show that individuals who perceive themselves to be lower in the social order often undergo a chronic physiological stress response. Furthermore stress has been shown to be more prevalent in more unequal societies. This response is associated with an increase in the production of stress hormones which produce various physical effects associated with a response to stress. Although in the environment we evolved in, these responses may have been useful in ensuring our survival in the face of danger i.e. the so called fight or flight response, in the long term under the conditions of chronic stress that can exist for disadvantaged groups this has been linked to negative health effects. The most prominent example of such a negative physical effect of stress is a poorer level of cardiovascular health (Marmot, 2004). This has been used to partially attribute poorer states of physical health to individuals in disadvantaged groups such as lower socio economic groups, individuals with lower levels of education, minority groups and immigrants. This concept of the power of relative social positioning to directly induce health problems has also been recently used to explain why more equal societies do better in the book *the Spirit Level*(Wilkinson & Pickett 2010). Given that stigmatisation results in a lower sense of individual esteem and a lowered perception of one's perceived place in the social hierarchy it can also result in stress and its negative effects on physical health. Another possible negative of such chronic stigmatisation is depression (Deacon, 2006) which is harmful in itself but which can also increase the likelihood of substance abuse and other harmful behaviour.These negative physical effects provide an important reason for the avoidance of stigmatisation where possible. Such negative effects should be taken into account when planning public health campaigns and be taken into account when assessing the potential benefits that might be gained from a particular course of action. This is because if such effects were ignored in the planning of a public health response to infectious disease it is possible that an another set of medical problems (related to stress and stigma) will be created in order to avoid those associated with the infection in question.

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[7] There exists for example the well-documented occurrence of HIV positive men in the 1980s who feared seeking treatment as they would face the assumption that they were homosexual or bisexual.

2.2 Indirect Effects on Health

In addition to the direct stress response that can be invoked by stigmatisation there are a range of indirect negative effects that can be created. These reasons, which are outlined in this section can be attributed to the notion that stigmatisation brings with it a reinforcement of a notion of self-loathing or lack of individual self worth (Courtwright, 2009). This alters individual behaviour so as make in several ways that can bring about negative consequences.

Reduced Desire to Seek Healthcare When Needed

Differential treatment of health individuals in the healthcare process can cause or worsen an already pre-existing situation of stigmatisation than results because of the individual being part of a minority group. Such groups can range from the classic examples that are prone to stigmatising and discriminatory behaviour (e.g. racial, religious, sexual orientation, age) to more specific groups that only arise in specific healthcare contexts. This latter group for example might include individuals that choose to lead unusual lifestyles, individuals that utilise alternative forms of medicine and a host of others. Whatever the group in question, individuals that form part of these groups can feel that in attempting to obtain healthcare that they are the subject of stigmatisation as a result of their membership of the group in question (Gornik, 2000). Black or other groups with a perceived lower socio economic status are slower to seek treatment for example than their white counterparts. This is likely because they feel they are to be judged more responsible for the condition through irresponsible behaviour than the white peers (Chesney, 1999). The same logic also applies to other groups who feel that the fact they belong to an already stigmatised group might be used in order to attribute blame for their having contracted their condition in question. This may explain why homosexual and intravenous drug injecting individuals are slower to be tested and seek treatment than heterosexual individuals or individuals that have contracted the HIV virus through a blood transfusion. In addition to the general public, such sentiments are often fostered by the healthcare profession itself, it has for instance been reported that healthcare professionals would rather treat HIV+ individuals in these latter groups than those coming from the homosexual or drug injecting community who are often perceived of as having engaged in irresponsible behaviours. Public health campaigns must take into account this issue for two reasons. Firstly they should seek, where possible, not to exacerbate pre-existing stigmatisation which result in a yet further reduced interaction with health services for individuals concerned. Secondly public health information campaigns, including those used in outbreaks of infectious disease, must take into account that individuals who are stigmatised may have an increased aversion to using medical services. Specially tailored or targeted approaches for such groups may therefore be needed in order to ensure efficacy of the campaign in question.

Reduced Motivation to Seek Benefits in Life

Individuals that are the subject of stigmatisation often suffer a lesser motivation to secure important resources in societal life. This lesser motivation stems from the negative experiences such individuals (or members of their cohort) have had in attempting to secure such goods in the past (Gornik 2000). This produces a desire to avoid similar negative and judgemental responses in the future that manifests itself in reduced efforts to secure important recourses such as public services which are available to all. Such resources can include aspects such as education, healthcare and employment opportunities (Courtwright, 2009). This reduced motivation means that stigmatised groups will secure fewer of the resources in life that are needed than those groups that are not stigmatised. The result of this is that stigmatised groups will have a lower standard of living than non-stigmatised groups. This often produces a consequent reduction in health status for such individuals. This concept, whereby an individual lowers his or her expectations in life as a result of his or her social position in society has been termed as 'adaptive preferences' in economics (Elster 1985). In the healthcare sector the practical result is often individuals from stigmatised groups demand (and therefore receive) lower levels of education and lower quality employment than their non-stigmatised peers. It has been demonstrated that lower levels of education and lower incomes have a clear association with lower levels of personal health resulting in disparities in personal health levels between stigmatised and non-stigmatised groups (Courtwright, 2009). Medical authorities should, during the context of an epidemic aim in so far as is possible not to further worsen such problems.

A Perception of Physician Bias – The response of medical professionals can be important in the decision of stigmatised individuals to seek medical attention. Individuals are less likely to seek treatments from individuals that hold stigmatising views. This is an important factor which may help in explaining why even in societies that create systems of equal access to healthcare do not always see the same levels of utilisation for the various groups that make up that society. For example it has been identified that black pensioners in the US are less likely to access preventative services such as influenza vaccinations than there white counterparts, despite the fact that such services are available on a free basis to both (Gornik, 2000) (This distinction also applies for numerous other procedures including testing services.). This may be explained by the different perceptions various societal subgroups have of their own existence. Such perceptions may vary according to subgroups such as age, race, sexual orientation and socioeconomic status. Individuals from poorer sub groups are for example more likely to have had exposure to experiences in their past or upbringing with obstacles to obtaining services. This could be from direct experiences or it could have happened to other individuals in their community. It has been postulated that such experiences can create future negative expectations that discourage individuals from seeking medical treatment. Individuals in the black community in the US for example can often have mistrustful attitudes towards public service providers, including healthcare providers that are offering potential vaccination services. The same logic may also apply to individuals in poor socioeconomic sub groups. Individuals in such subgroups may have a more fatalist attitude towards health issues than those who come from more advantaged sub groups and who as a consequence have been more used to securing beneficial healthcare in the past. Individuals from such groups may be accustomed to receiving attitudes of "courtesy, consideration and fair treatment" and so may seek medical services in the knowledge the expectation that they would experience such attitudes once more.

The foregoing discussion demonstrates the possibility of stigmatisation to have an impact on individual health in several different ways. The first by directly inducing a chronic stress response that is associated with health problems. The second is by altering individual behaviour so that stigmatised groups are less likely to seek healthcare than non-stigmatised groups. The third mechanism exists where individual motivation to secure the resources needed for a successful life are altered according to their perceived low position in society. The result is a low standard of living with a consequent lower level of individual health. In all of these areas it will be important for those tasked with responding to outbreaks of infectious diseases not only to ensure that such factors are not unnecessarily exacerbated and also to ensure that such issues are adequately considered when projecting the expected efficacy of a project. The following section of this document will present some examples of where stigmatisation issues have been recorded during the context of an outbreak of infectious disease.

Stigmatisation and Acute Infections

The reader will be aware that the foregoing discussion concerning the negative effects of stigmatisation was based upon research that had been concerned mostly with stigmatisation that exists as a result of chronic issues and not as a result of acute issues. The first category would include conditions such as those already described e.g. HIV, Hepatitis B etc. When discussing acute issues one could imagine conditions such as Influenza, SARs or outbreaks of some other agent that usually causes a short lived infection. An important question to consider is which of the negative outcomes of stigmatisation described above will apply in the acute contexts described here. It seems likely that the direct effect associated with the physiological stress response to chronic stigmatisation is likely to have little relevance in such contexts. Such responses arise through long term exposure to long term social pressures. The social pressures that would apply to individuals a result of epidemics of a transient nature would also be transient in nature and so would be unable to bring about the long terms stress responses needed to directly result in physiological damage. Of likely more relevance will be issues associated with health avoidance (Barrett & Brown, 2008). Potential problems could be associated with healthcare avoidance by individuals that would feel stigmatisation during the context of an epidemic. Such groups could feasibly include individuals in lower socio-economic groups, immigrants, the homeless, the elderly, and individuals with compromised immune systems (O'Sullivan & Bourgoin, 2010). Each of these groups has, as a result of its particular circumstances a higher chance of acquiring infections or having infections of a longer lasting nature during an epidemic. As a result each of these groups may be consider to pose a higher risk during an epidemic and may, as a result, subject to stigmatisation. The poor, immigrants and homeless often live together in larger numbers and in more confined spaces than other groups. As a consequence they are more likely to contract an infectious agent that is causing an epidemic. The old and those have compromised immune systems (for example individuals with HIV) are more likely to have longer lasting infections, shed more of the infectious agent in question and, as a consequence, infect others at higher frequencies than might be the case for a member of the general population. Each of these groups will suffer stigmatisation under normal circumstances, stigmatisation that may worsen in the context of an epidemic.[8] It is therefore conceivable that such groups might be more likely to engage in treatment avoidance behaviours during an epidemic of infectious disease. Public health response planner should therefore take such factors into consideration when planning potential responses to pandemics.

3. Documented Experiences of Stigmatisation in Epidemic Situations

There have, in the last decade been several prominent outbreaks of infectious disease on an international scale. These include the SARS outbreak of 2004, the outbreak of Avian Influenza in 2005 and the H1N1 pandemic of 2009. These, and other outbreaks provide useful study cases for many aspects of epidemiological strategy including the possible stigmatising effects of communications strategies designed to confront such epidemics. Research on instances of discrimination and stigmatisation, as a result of these crises, have helped to illuminate some of the issues that have arisen as result of the communications strategies designed to combat these outbreaks. Hindsight has shown that in each of these instances the perceived threat proved not to be as severe as hadinitially been feared. This was however not known at the

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[8] The risk for pre-stigmatised groups of suffering further stigmatisation during an epidemic is discussed further in section 3.3, page 23

time of these outbreaks, when considerable fear and uncertainty existed. Often, during the early stages of epidemics the lack of official information creates a gap that can be filled by rumour and misinformation. This environment creates fertile conditions for stigmatisation effects are created for certain categories of individuals and also examples of detrimental effects that occurred as a result of such stigmatisation.

In such conditions, where a lack of official reliable information is available, individuals seem likely to grasp at whatever is available, even though the reliability of such information may be questionable. One study for example showed YouTube to be a prominent source of information for the general public during the H1N1 epidemic of 2009. Whilst this provided a useful medium for agencies such as the CDC to distribute accurate information it also provided a medium for the dissemination of inaccurate information. In this study 21% of videos on youtube were found to be misleading (Pandey et al, 2010).Such easily available information accommodates an instinctual desire of individuals to create categories of 'others'. This can be seen as a negative effect of the positive ability individuals have to identify common interests with other individuals and to engage in co-operation with such individuals. Often the sense of solidarity that such individuals feel with each other comes at the expense of those who are not perceived to share the same interests. This can be seen in the way that popular media often demonises individuals who come from other countries and are seen to be profiteering unjustly from public health care services.[9] In these situations the common sense of solidarity between individuals that can identify with each other is reinforced by efforts to isolate those who fall outside this group. With HIV for example an 'us' and 'them' mind-set has often been described (Maywar et al, 2010). This need to isolate outsiders, those who are not perceived to share the same interests can also extend to those perceived to be a threat in terms of communicable diseases. In such situations society as a whole may feel threatened by groups or categories of individuals that are perceived to be a greater threat in terms of communicable diseases. Often moral culpability may be attached to conditions where lifestyle factors can play a part. Threats of this kind can perceived as emanating from a wide range of individuals. These can range from the obvious i.e. those suspected of acutely carrying an infectious disease and exhibiting the requisite symptoms to others who are deemed more likely, because of their pre-existing health status or their behaviour, to be susceptible to infection. Such individuals could be those who live or work in close proximity to those who might be infected or those that emanate from a region where the disease in question is more prevalent. The stigmatisation that these and other groups may be exposed to as a result of epidemics is described below.

3.1Stigmatisation Based Upon the Perceived Geographic Origin of an Outbreak

Epidemics of infectious diseases have often been linked in popular perception to groups of individuals that have a particular origin. In 1892 outbreaks of typhus fever in the US were linked to immigrant Russian Jews (Kraut, 1998). In the 19th century the Irish in particular were blamed for the scourge of cholera. Later in 1900, the Chinese community in San Francisco was the subject of vilification after an outbreak of bubonic plague resulting in extreme discrimination for individuals from that group. The great influenza pandemic at the end of the first world war was mistakenly given Spanish origins by many (Barry 2004). More recently an outbreak of hantavirus in the southern US was attributed to native Americans and dubbed the Navajo

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[9] See for example the article in the UK's Daily Telegraph of 19 March 2011. This article was in response to concern that too many foreigners were coming to the UK merely to gain access to the health service there. http://www.telegraph.co.uk/news/uknews/immigration/8391274/Health-tourism-why-the-NHS-became-popular-destination.html

disease. This outbreak led not only to incidences of discrimination against the Navajo but all native Americans in the region (Pearson et al 2004). The Chinese community around the world was again the source of negative attention in 2003 with the SARS outbreak. A Centre for Disease Control analysis of SARS related phone calls in April – May 2003 (during May 2003, 7,327 SARS-related calls were received; 4,013 (54.7%) of these calls were passively sampled) showed that an average of 10% of callers expressed concerns related to fear, stigmatization, and discrimination. Major concerns included the following: fear of buying Asian merchandise (187 calls); working with Asians (83 calls); living near Asians (45 calls); going to school with Asians (41 calls); and more generic issus such as being on a cruise ship or airplane (77 calls); and church, school, or workplace issues (65 calls) (Xinyu Jiang et al, 2006). Similarly in Europe in the study covering the United Kingdom and the Netherlands Chinatowns major cities experienced a drop in numbers of tourists and local Chinese customers, whereas Chinatowns and Chinese restaurants in other cities also reported a drop in local Chinese customers. Travel agencies specialising in Far-east Asian regions also reported trade losses. Some respondents reported that they had lost their jobs as a result of reduced business. Tensions between residents and visitors/returnees were reported in response to rumours about local SARS cases and failure of quarantine practices. Some respondents felt discriminated against, particularly by the way in which the media linked SARS with Chinese people.

In 2009, during the H1N1 pandemic the worldwide Mexican community was the subject of unwelcome attention due to the fact that Mexico was perceived as being the origin of the new virus. The outbreak came to be called the Mexican flu in many states because it was thought to have first originated there and despite the fact that this fact would have little to do with the future propagation of the virus. (Gallagher, 2009) Information on the possible origin of an infectious agent are often the source of fear an anxiety. This was evidenced during the H1N1 outbreak in 2009 by ships refusing to dock in Mexican ports, even in areas where there had been no incidences of infection, but which were willing to dock in US areas where infections had actually occurred.Haitian officials decided that turning back a Mexican ship carrying humanitarian food aid was warranted because of H1N1 fears.[10]Whilst there is undoubtedly a logical purpose in outlining where an outbreak is occurring so that individuals can be vigilant and, in appropriate circumstances, avoid unnecessary travel to the affected region, this information led to Mexican individuals experiencing numerous problems around the world and even in their own country. The identification of Mexico as ground zero of the emerging pandemic justified many instances of repressive policies against Mexicans in other countries such as the employment of unnecessary quarantine procedures (Perry & Lenhoff, 2010). Mexican citizens were for example confined by Chinese health officials despite having no flu symptoms or any other illness in the cities of Shanghai, Hong Kong, Beijing and Guangzhou.[11]Reports indicated that quarantine measures in Beijing were extended even to Mexicans who lived in Beijing and who had not recently visited Mexico.[12] In the US, conservative media personalities on many occasions blamed Mexican immigrants for spreading the disease across the border, continuing their scapegoating of immigrants.[13]In a national survey on swine flu in April 2009 17% of respondents reported "avoiding

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[10] Mexico City Businesses Reopen, But International Fears Persist, *CNN* May 6, 2009- http://edition.cnn.com/2009/HEALTH/05/06/swine.flu.mexico/index.html

[11] Mexico City Businesses Reopen, But International Fears Persist, *CNN* May 6, 2009- http://edition.cnn.com/2009/HEALTH/05/06/swine.flu.mexico/index.html

[12] Human Rights Watch, Swine Flu Measures No Excuse for Abridging Rights, May 18, 2009 http://www.hrw.org/news/2009/05/18/swine-flu-measures-no-excuse-abridging-rights

[13] Allison Tom, Paranoia Pandemic: Conservative Media Baselessly Blame Swine Flu Outbreak on Immigrants, *Media Matters for America* April 27, 2009, http://mediamatters.org/research/2009/04/27/paranoia-pandemic-conservative-media-baselessly/149558

Mexican restaurants or stores" out of concern over swine flu.[14] The stigmatisation and discrimination of Mexicans led to statements of condemnation by the Anti-Defamation League[15]and Human Rights Watch.[16]

In addition, highly visible infection control measures used against individuals that have recently travelled from high risk areas (such as compulsory examinations) can, in the mind of the general public, act to focus attention upon immigrant groups that are trying to enter another country. The very act of naming a country of origin appears to aid individuals and mainstream society in focusing on a group perceived as being outsiders or different than mainstream society. As described above, such a notion is central to many conceptions of what stigmatisation entails. The identification of a small minority group that is likely to pose a risk to the other members of a society is therefore likely to lead to stigmatising effects. Caution should therefore be taken where health communication strategies intend to identify one minority as posing more of a risk than the rest of society as a whole. Negative reactions to such identification appear to more likely if the group in question is already the subject of stigmatisation or discrimination. During the SARS outbreak for example, the general American population's distaste of some Chinese eating habits appeared to manifest itself with for example one Newsweek article for stating that the Chinese should question their habits of eating raw meat (Eichelberger, 2007). This was despite the lack of evidence at the time that there was any connection with Chinese dietary habits in the US and the spread of the disease. Even individuals who have no connections with affected countries can find themselves subject to such stigma. This can be the case where an unfamiliar host culture casually groups different minority cultures into one. This occurred in the SARS outbreak for example where not only the Chinese community felt itself the subject of stigmatising attitudes but also other south east Asian groups that were present as minorities in western societies (Schram 2003). In one incident, the Vietnamese owner of a Chinese restaurant read a completely mistaken report in the local press that he had succumbed to the syndrome. In the SARS outbreak a non-scientific message of an airborne agent that was spread by the Asian community was prevalent amongst the general Canadian public. In Canada, visits by non-Chinese individuals to Chinese restaurants plummeted, real estate agents were told not to bring potential buyers of Chinese ethnic origin to see properties. An intense panic had taken hold around the Toronto area, much of it focused around the Asian community because one woman had brought SARS from a trip to Hong Kong to Toronto. This was despite the fact that no official advice had been issued stating that the Chinese community in general was a cause for concern and that public advice in Canada was focused around avoiding contact with hospitals where possible. This demonstrates the ability for groups to become stigmatised even where no official sources have given valid reasons to suspect that the group concerned poses more of a danger than any other group. Usually such responses are not rational as the individuals who are members of such minorities may have been living in the host country for many years without having travelled back to their country of origin. Such individuals will likely be no more likely to infect others than other members of the general population. Other individuals may have travelled back to other regions of the state of origin or may have had no contact with anybody likely to be infected. This situation therefore presents a positive role for medical authorities to act during epidemics by dispersingaccurate information in order to dispel urban myths that may be both false and harmful.

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[14] Blendon RJ, SteelFisher GK, Benson JM, Weldon KJ, Herrmann MJ: Influenza A(HIN1)/Swine Flu Survey III. http://www.hsph.harvard.edu/news/press-releases/files/Swine_Flu_Topline_7.15.09.pdf

[15] ADL Condemns Demonizing of Mexicans for Swine Flu Outbreak, 1 May 2009, http://www.adl.org/PresRele/DiRaB_41/5516_41.htm

[16] Human Rights Watch, Swine Flu Measures No Excuse for Abridging Rights, May 18, 2009 http://www.hrw.org/news/2009/05/18/swine-flu-measures-no-excuse-abridging-rights

3.2 Stigmatisation Based Upon Animal Origin

The H1N1 Influenza virus was, in addition to being popularly known as the 'Mexican flue' was also known as the 'swine flue'. This resulted not only in negative outcomes for humans but also for pigs and the agricultural sector involved in producing pork. Numerous media stories were reporting the connection between the virus and the porcine industry. This resulted in a reduced consumption of pork and also fear of those individuals such as pig farmers who worked in close proximity to pork. These reactions likely caused considerable economic damage to individuals and regions that depend heavily upon the pork industry. This also appeared to provide fuel to religious prejudices against the pork industry in lands such as Egypt where the prevailing religion amongst the majority deems the consumption of pork to be unacceptable. This lead to the slaughter of the entire pork stock in that country. This was despite the fact that there was no real danger from exposure to pork whether it was dead or a alive. Whilst the virus in question had likely arisen from a recombination of various genetic materials in an infected pig, this was a one time event. As a consequence, pigs presented no running health risks to humans despite the name 'swine flue' being commonly used.

It appears therefore to be necessary for health authorities to be very careful when attributing origins to outbreaks of infectious disease. Such information can risk stigmatisation of individuals that originate from the region concerned. This is especially true when describing the virus itself. Care should be taken not to use language that could lead to emotive and irrational inferences being drawn. References such as 'Mexican flu' or 'swine flu' should be avoided in favour of more technical language in order avoid problems like those that have been described above.

3.3 Individuals that Fall into Pre-Stigmatised Groups

In addition to individuals with a geographical link to the origin of an outbreak, other already stigmatised groups are more likely to suffer from an increased level of discrimination. In particular those minorities that were perceived to already have higher level of disease within their community. Groups such as the homeless, the homosexual community and those that are drug users can suffer increased levels of discrimination during outbreaks of infectious disease (Williams et al, 2011). In the great influenza pandemic of 1918/19 the poor were feared as carriers of the disease because they lived in cramped living conditions (Barry, 2004). The perceived increased incidence of disease within these communities increases the perceived risk of them being carriers of whatever infectious agent might be responsible for a recent outbreak of infectious disease. This can result in an increase in the level of prejudice such groups are subject to during an epidemic (Goodwin et al, 2009). The stress and negative affects that any of these stigmatised groups is likely to be increased in the context of an outbreak of infectious disease.

Unfortunately the fear and negative stigmatisation that is engendered against certain groups within populations during an epidemic can hinder efforts to manage an epidemic of infectious diseases.[17] This has been clearly demonstrated for example with attitudes toward testing for HIV (Chesney, 1999) and treatment where black (Gornik, 2000) or other groups with a perceived lower socio economic status are

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[17] Centres for Diseases Control and Prevention (1993) "Hantavirus infection – Southwestern United States: interim recommendations for risk reduction *Morbidity and Mortality Weekly Report* (*MMWR) 42(RR-11); 1-13*

less likely to seek treatment than other groups. The fact that the stigmatisation of such groups feel can increase in times of epidemics means that such groups are even less likely than they would be normally to seek treatment if they suspected that they had contracted the infection in question. It is important therefore that during the early stages of an epidemic that special attention will be needed for such groups in order to increase the chances that they are likely to avail themselves of treatment and limit where possible harmful healthcare avoidance behaviours.

3.4 Stigmatisation Experiences of Individuals as a Result of Infection

During a pandemic it may be perhaps stating the obvious to say that the group of individuals that will experience the most stigmatisation issues are those who become infected. The stigmatisation of other groups (other than those who are infected) in a epidemic situation is based on assumptions by other members of the population that these groups, by virtue of their various characteristics, are at increased risk of infection and therefore pose a threat. Individuals who are actually infected obviously pose a greater 'threat' than those who may be infected and so will be subject to a higher level of stigmatisation. Individuals who become infected therefore suffer from two conditions, the disease itself and the stigmatisation that comes with infection. Such stigma can, depending upon the disease in question, often entail a greater burden than the infection itself. A classic example of such a condition is leprosy, which can be cured with anti-biotic. Unfortunately though the social affects of having such a disease can often last a life time (Barret & Brown 2008).

The SARS outbreak provided a recent example of the potential stigmatisation issues that individuals can face (even after their deaths). (Kleinman & Lee, 2005) In China, instances of stigmatisation and discrimination included refusal by some funeral homes to handle the bodies of SARS victims, reluctance of certain medical and paramedical staff to care for SARS patients, discrimination of health professionals, e.g. refusing a service in the barber shop, forcing of employees to take annual leave as they had recently been to the hospital or to parts of mainland China where SARS. Cases also included refusal of basic services to people who were not infected but residing in buildings associated with SARS. Residents of Amoy Gardens, a residential complex with 17,000 inhabitants where a significant number of SARS cases occurred, were isolated in camps and shunned by co-workers and schoolmates, who would not share elevators or hallways with them. During the outbreak of SARS, the Equal Opportunities Commission of Hong Kong filed 79 formal complaints and received hundreds of inquiries from the general public on issues of worry about contracting SARS, and attitudes to stigma and discrimination related to SARS. Complaints were predominantly connected with unfair treatment in the workplace (70%) and denial of access to goods and services (29%) (Sting Lee et al, 2003). A survey of residents of Hong Kong, Taiwan, and Singapore was conducted in order to understand public's reaction to the possible use of widespread quarantine. The use of quarantine was widespread in these three countries during the SARS epidemic. The report concluded that worries about social stigma were more common in Taiwan than in the other three countries. Approximately two-thirds of those in Taiwan said that they would be very worried about being treated unfairly after the quarantine period was over because people might think that they were still contagious or because of their economic or social status. Approximately one-third in each of the other regions reported that they would be very worried that they might be treated unfairly for these reasons (Beldon et al, 2006).

Such stigmatisation issues can often worsen the impact of an epidemic, both for the individual itself and society at large. This occurs where infected individuals perceive the social cost of the stigma related to acknowledging their condition to be higher than the cost of forgoing treatment by keeping the condition secret (McGrath, 1992). Where the balance lies will often depend upon the disease in question. Some infectious conditions carry with them a far greater potential for creating of social stigma than others. HIV orHepatitis B is for example associated to a far greater extent with stigmatising responses than influenza.

In order to reduce the perceived social cost of acknowledging that one is ill and seeking medical help protection of individual privacy will be important. This may involve allowing individuals thepossibilityto seek care in a manner that will not unnecessarily compromise there personal privacy. This could involve a variety of factors. It may include the physical location of any treatment facilities (see the discussion on vaccination below) or it may concern sensitive handling of their patient record. In some cases this may mean not adding too much information regarding their condition to the record in order to assuage individual fears (rational or not) that the presence of their condition on their record will be used in a negative fashion by future employers or insurers. The availability of anonymous testing facilities for HIV is a good example of this idea already in action. One striking example involved an attempt to offer anonymous services of this kind at a distance using home collection of samples and telemedicine based consultation (Frank et al, 1997). It has been shown that such facilities attract individuals towards testing who would not otherwise do so under different circumstances and has allowed them to modify their behaviour, reducing the risk to other individuals (Kegeles et al, 1990), (Hetz-Picciotto et al, 1996). The removal of such facilities has been associated with a reduction in these positive aspects (Kassler et al, 1997).

Reporting of infections will also be important consideration. Some jurisdictions require the mandatory reporting of cases of infectious disease(e.g. HIV and Hepatitis C) to national health bodies so that the situation on the ground can be better evaluated (Stoto, 2008), (Sagmeister et al, 2002). This can be of use in providing important and timely data on the progress of epidemics. This may involve the transmission of individual patient records to central medical authorities (Gostin et al, 1997). Such methods can however raise concerns with regards to privacy and potential stigmatisation issues for the individuals who are involved. In addition the legality of such methods may be dubious, especially in Europe where stringent data protection measures are in place concerning the use of medical data.[18] The availability of anonymous testing and possible even treatment may therefore be both legally encouraged but also medically efficacious in that it would likely mean that an increased number of individuals would feel less restricted by potential stigmatisation and seek treatment for their condition. This would not only have a positive effect on the individuals directly concerned but on society as a whole which would benefit from the decreased rate of transmission that increased testing and treatment would bring about. It is important however to note that in order to take advantage of the benefits that an anonymous environment would offer it would not be enough to have anonymous testing procedures in place, but such procedures would have to be actively publicised and disseminated so that individuals were aware of them (Herek et al, 2003).

‘*Democratic’ Epidemics and Stigma*

The level of potential stigmatisation is not necessarily related to the risk of infection. An average individual is at far greater risk of contracting influenza for example than HIV. In addition, the fact individuals can take measures to ensure they can avoid infection with conditions such as HIV seems to have a lesser impact.

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[18] See page 52 for a brief description of the data protection requirements concerning patient medical records

This is in contrast to the less stigmatised situation with influenza where individuals are able to do relatively little to guarantee that the do not become infected. In this sense influenza has been described as a 'democratic' disease, with potential of infecting individuals from all sections of society irrelevant of class of lifestyle factors (McGrath, 1992). On the contrary it usually seems to be the case that stigmatisation is strongest where it is possible for individuals to take precautions that will significantly rule out the prospect of them getting the disease. One could possible surmise that this is in line with an explanation for stigmatisation that is routed in evolutionary psychology. This would see stigmatising behaviour as an evolved trait that is used to isolate potential dangers and thus reduce risk for those that are stigmatising. If such a concept were true stigmatisation would be more likely to be employed where it could actually work. In the case of epidemics this might mean where stigmatising behaviour results in a reduced chance of infection. With conditions such as HIV one could theorise that stigmatisation exists in order to isolate individuals from society and keep them at a distance. Infection with such a condition will often be associated with certain lifestyle behaviours that are more prevalent in certain minority groups in society such as certain sexual activities or intravenous drug use. With more 'democratic' conditions such as influenza though it is often not possible to tie such conditions to individual characteristics. Such conditions are perceived as being able to strike any one and in all groups in society. There may be little reason to stigmatised individuals with such conditions as any other individual and their family member might be at equal risk of contracting the condition in question when you have as much a chance as them as contracting the condition in question. Where on the other hand membership of a minority, be it ethnic, socio economic, based upon sexual orientation or behavioural aspects means an increased risk of infection individuals may perceive that their chances of infection are lower and so may be more likely to engage in stigmatising behaviour. Given the lower risk they perceive themselves to have of infection, the most beneficial strategy may be deemed to stigmatise, resulting in isolation and minimisation of their own risk.

Another potential explanation for the differences that occur for the varying stigmatising potential of various diseases has been the length that the effect of a potential infection lasts. This has been linked to Goffman's idea (Goffman, 1963) that stigma represents a situation whereby individuals are disqualified from full social acceptance (Weiss & Ramakrishna, 2004). This idea fits with the extra stigmatization that conditions such as HIV or Hepatitis B or C carry in comparison to conditions like influenza. Illnesses such as the first two often bring with them chronic or even life long social problems. Influenza however (assuming the individual in question recovers from it) is unlikely to bring about long term health issues that make social interaction difficult. Some commentators have in line with such thinking described the level of stigma being associated with a disease as being a measure of the level of social risk that that disease carries (Burris, 2000). Thus, conditions in the first category may be more concerning for our socially concerned minds which fear social exclusion above most other aspects, perhaps even than the loss of life itself. If such an idea were correct it might explain why individuals that are infected with chronic conditions that are relatively difficult to transmit (such as HIV) are stigmatized more than individuals who are liable to carry more easily transmissible conditions such as influenza which are not likely to entail long term health problems and their associated issues of social inclusion. These are issues of stigmatization which the planners of responses to epidemics should take into account in order to maximize the effectiveness of their response.

3.5 Stigmatisation Issues Associated with Vaccination

Vaccination is one the most effective methods of combatting outbreaks of infectious disease (Ehreth, 2003). Vaccination is generally a cheap intervention that can be carried out both before and during an infectious disease outbreak. Vaccinations often have a high efficacy with a low risk of negative side affects. Unfortunately take up of vaccines by both the general population and at risk groups is often at a level below that which may be desired by public health authorities. Fear of undesired side effects or doubts over vaccine efficacy are two prominent reasons. Another irrational fear that many individuals often have is that there is a risk that they will become infected with the virus in question after vaccination. This is based upon the fact that individual or incomplete components of the virus are often used as the basis of vaccination (Streefland 2003). Another however is fear of stigmatisation. Whilst certain conditions are often regarded as relatively democratic (such as influenza) (Barret & Brown 2008), having the ability to affect everybody regards of wealth of lifestyle, other infectious diseases carry with them an added burden of a high level of stigmatisation.

One source of stigmatisation that may surround infection with a disease may be attributable to certain lifestyle behaviours that are associated with an increased risk of infection. HIV provides an obvious example. Groups often at highest risk of HIV infection are often those thought to be associated with lifestyle behaviour that might be considered undesirable by a large part of the population. These include homosexuals, drug users and sex workers. Hepatitis B and C and Human Papilloma Virus (HPV) are other examples of conditions that carry with them a high level of life style stigmatisation. With each of these conditions individuals are not only stigmatised because they have the condition in question but also because the condition carries with it connotations of certain lifestyle behaviours. The possible issues of stigmatisation present not only a problem for those who are infected with the condition but also with those contemplating a vaccination. This is often because individuals fear that accepting a vaccine will be a signal to others that they partake in stigmatised activity. HIV vaccine trials for example have encountered difficulties recruiting individuals who fear that they will be stigmatised as being sexually promiscuous or as intravenous drug users (Nyblade et al, 2003). This is because such individuals fear that this will be the logical assumption that individuals would make upon learning that they had chosen to be vaccinated. The fear of stigma often appears to be higher from women who fear a negative response from their partners who they feel may suspect that they are engaged in promiscuous activity out side the relationship. The same may also be true for parents who are considering vaccinating their children. Some parents for example have reported fearing the social response of having their children vaccinated against HPV fearing that their children will be associated with ‘undesirable activity’ (Dawson, 2005), (Wong & Sam 2007).

Vaccination targeting

In considering whether to provide vaccination to the entire population or to certain groups within society medical authorities will often use cost benefit analysis to discern whether the benefits deployment of vaccine justifies the cost. The results of such an analysis may sometimes suggest that the vaccination of the entire population may not be cost effective and so will not be pursued. In such circumstances it may be more effective to target only at risk groups. Such groups may for instance be at risk because for lifestyle reasons or other reasons such as health status (e.g. those who are elderly or obese). Whilst this may make complete sense in terms of an argument based on the limited allocation of resources it can raise further issues with regard to stigmatisation. This is because the targeting of only certain minorities by states for vaccination can increase the risk of stigmatisation for such groups. When states target such minorities they must inform the public which minorities are to be target for vaccination. Often this will be accompanied by information detailing why such minorities should be targeted, perhaps highlighted the attributes of such groups in order to attract their attention. Whilst the aims of such efforts may be benevolent, one negative effect is that they may act to distinguish such minorities in a negative light in the eyes of the general population. Such information might for example highlight lifestyle behaviours that are viewed negatively by the population in general (Dawson, 2005). As has been discussed in this paper one negative consequence of stigmatisation is that it causes those who are stigmatised to avoid healthcare behaviour. When groups are selected for vaccination because they have vulnerable conditions such as old age or obesity there is also a risk of stigmatisation or alienation. Elderly individuals may for instance resent being categorised as a vulnerable group. Such labelling may add to feelings of loss of power and weakness already associated with aging (Mordini & De Hert, 2010). The elderly form a heterogeneous group; whilst some may be infirm others may, at the same age be relatively healthy. Such individuals may resent such a categorisation and feel stigmatised or estranged from general population as a result.

It is therefore possible that targeting individuals through public health messages can, if not managed properly lead to negative health effects for the target group. It is therefore important that medical authorities take care when deciding to target certain groups for vaccination in preference to making such vaccination available to all. Publicly available information will have to be crafted carefully. This will be especially true when explaining why some groups are being singled out for vaccination whilst at the same time avoiding stigmatisation of such groups (Streefland 2003). If such a course is followed it should be followed with due caution adopting an approach that minimises as much as is possible risks of stigmatisation. The use of educational measures has been advocated for this purpose. In addition it is important that those administering vaccinations do so in a considerate a sensitive manner. Another important aspect to consider is how and where vaccinations are to be administered. If possible, attempts should be made to avoid associations with behaviour that is stigmatised. This might mean avoiding selecting sexual health clinics or drug addiction clinics as locations where vaccines are to be administered. Even the urban areas selected may be important, with certain individuals not wanting to be seen entering areas that have a bad reputation or preferring to use a location that is discrete (Newman et al, 2010).

Universal Vaccination as A Solution

One possible solution that has been suggested for the problems that have been described here is to offer vaccination on a general basis and not to targeted groups. This has for example been recommended for the Hepatitis B vaccine (Dawson 2005). Such an approach would avoid unnecessary stigmatisation of targeted groups and also ensure that targeted groups are actually vaccinated by virtue of them being part of the general population. The negative side of such an approach would be however that this would involve the deployment of resources in a manner that was not cost effective. This might mean that other cost effect treatments could not be offered elsewhere. In addition there are also ethical concerns over the exposure of low risk individuals to the risk of an adverse reaction to vaccination. Although such risks might be extremely low it might be considered ethically dubious to submit individuals that have little risk of contracting the condition in question to the risk of adverse reactions to vaccination. Additionally it might be likely that at the beginning of an epidemic the available stock of the any vaccine might be limited. If this is the case then it might be both wasteful and also ethically dubious not to target the available stock on individuals who are at the greatest risk of contracting the infection in question.

3.6 Medical Professionals

Medical professionals, in the course of any epidemic, spend large amounts of time with numerous individual that are suspected of being infected or are indeed actually infected. This can make them prone to stigmatisation issues. General practitioners that have for example been involved in treating infected individuals have been shown to be susceptible to stigmatisations. GP's who worked with SARS patients in china for example reported higher levels of anxiety and social dysfunction (Verma et al, 2004). Stigma of this type flows from the fact that such workers are perceived as being at a higher risk of infection. Doctors involved in the treatment of HIV patients for example have reported feeling at risk themselves from stigmatisation as a result to their close proximity to HIV+ individuals (Chesney, 1999). Healthcare workers may also face the treat of quarantine under certain circumstances. In the SARS crisis in Canada, healthcare workers accounted for almost a quarter of total infected cases (Flood & Williams 2003). Healthcare workers who are known to have worked with infected individuals can feel stigmatised not only by society at large but also by their colleagues who have not had the same contact with infected individual. The effects of such stigma can be long-term, even after the disease in question has disappeared. Those who had been quarantined during the SARS outbreak (including healthcare workers) reported being shunned and stigmatised for some time afterwards. Such individuals could face issues such as psychological stress, financial hardship in addition to effects associated with social stigma (Hawryluck et al, 2004). Quarantine has also been associated with instances of posttraumatic stress disorder. An obvious risk with stigmatisation of health professionals that are involved in treating infectious individuals is that the possibility of stigmatisation will make them less likely to react in an appropriate manner to the disease. This might involve certain categories of health professionals that avoid contact with individuals who are potentially affected. Another possibility is that healthcare professionals might be less likely to make a diagnosis or carryout suitable tests on the individual in question. Given the importance of correct diagnosis, monitoring and treatment on the course of an epidemic, stigmatisation of healthcare professionals could therefore have a negative effect on healthcare workers. Novel outbreaks of infectious disease can sometimes present significant risks of infection to healthcare workers, especially before the pathogen in question is correctly identified. In the SARS outbreak in Canada for example, the infection rate among healthcare workers treating those infected was high (Maunder, 2004). In addition, healthcare workers involved in the treatment of individuals during the early stages of an outbreak can feel blamed by other colleagues for allowing the infection to proliferate (Mitchel et al, 2002). Whilst SARS was later discovered to be relatively un-infectiousness this information was not known in the first weeks of the outbreak, where lack of information and fear were rife. Such a situation can create a stressful environment for the healthcare workers who are on the frontline of containing a potential epidemic (Maunder, 2004). This fear can spread to the wider community at large who, after those infected with the diseases in question, perceive those in close contact with such individuals i.e. healthcare workers to be the greatest risk. This can give rise to a sense of stigmatisation where healthcare workers can feel estranged from society at large. In the SARS outbreak, healthcare workers reported that individuals were not only avoiding contact with them on a professional basis i.e. missed medical appointments, but even that individuals in society at large had been avoiding contact with them and their family at social engagements. This sense of social stigmatisation added to the stress that health workers were already feeling as a result of being involved in the initial stages of the outbreak. Negative media reports and new stories over the performance and behaviour of healthcare workers can add to this sense of stigmatisation and stress. In Canada during the SARS outbreak for example news coverage was extremely critical of a nurse that was involved in treating SARS patients and had used public transport. She had become infected and had subsequently infected others. The coverage labelled her as stupid and questioned whether such healthcare workers should be using public transport at all. (Maunder, 2004). It has been documented in general that social support can act as an important buffer in protecting against the effects of stress. The potential effect of stigmatisation on healthcare workers to isolate them socially is therefore concerning. Such isolation can remove an important support that is available to healthcare workers during the stressful period that an outbreak of a hitherto unknown disease would represent. It is important in the context of an outbreak of infectious disease to aim to limit the affect that such stress has upon healthcare workers and the erosion of social support through stigmatisation that can occur. If this does not happen the situation may be worsened by a poorer performance of healthcare workers or even worse by a higher level of absenteeism. This could have a serious effect on the treatment of individuals and also the containment of the outbreak or epidemic in question in addition to the health and well being of such workers.

4. Possible Reponses to Stigmatisation Arising During Epidemic Situations

The proceeding pages of this document have shown that stigmatisation is capable of having harmful effects upon both the lives and the health of affected individuals. It has also been demonstrated that epidemic type situations can produce stigmatising environments for various groups and individuals. It is therefore important in the context of such events to consider strategies to minimise the amount of stigmatisation caused. The following pages will consider possible strategies that can be used to pursue this goal.

4.1 Stigmatisation and Self Respect as a Necessary Good

Democratic societies thrive upon the assumption that individuals are capable of making their own self-judgement about their own worth and the worth of the life they lead (Gutwirth, 2002). In a perfect world individuals would not, if they felt their chosen path of life to be the best option, necessarily be phased or deterred by the disapproving views of others. However as has been described above, a corrosive effect of stigmatisation is its ability to make individuals question there own self worth or to have a reduced level of self respect. This reduces the chances that they will pursue the activities needed to maximise the chances of securing their desired plan for life. It has been argued that ensuring that individuals can maintain their own self-respect is important in ensuring not only personal happiness, but also a high level of plurality that is essential in a democracy (Courtwright 2009). Self-respect allows individuals to disregard outside judgements and to be able to resist the urge to hide aspects of oneself as a response to a sense of self-disgust in others. It is thus not only a matter of moral principal but also one of good democratic governance that individual self-respect is fostered to the greatest degree possible. One must look at the experiences of stigmatised groups to discern what this entails in the context of health policy and more specifically epidemiological communication strategies. *Rawls* described the possibility to obtain self-respect in society as a primary good (Rawls, 1971). Self-respect, according to Rawls therefore has comparable importance in democracies as the well known civil and political freedoms such as the right to vote and the freedom of speech. Each of these rights or freedoms should therefore be present in a democratic society and are necessary for individuals to be able to pursue their own conception of the 'good life' as Rawls described it.

Society, according to Rawls, should therefore in order to be just, be established in a manner that permits individual self-respect. Given that a central aspect of stigmatisation is a corrosion of self respect it can be argued that states also have a duty to prevent stigmatisation. An important part of this is the attitudes of public institutions, including those concerned with elements of public health. Rawls described two important ways in which such institutions can act in order to protect individual ability for self respect and therefore to guard against stigmatisation.

4.2 Equal Treatment and Non Discrimination

Rawls postulated that, first of all, institutions must treat individuals equally, irrelevant of any societal group they belong to. Public services should be provided as far is possible on a non-judgemental basis and to all individuals in society irrelevant of which groups they belong to. Not only should such an aim be desirable, it should be a legal requirement. This is because it is only through a non-selective availability of public services that plurality in society can be protected. A society that only allowed individuals and groups deemed desirable to access its public services would not only be stigmatising but also restrictive of plurality and therefore not ultimately of democratic character. In the context of public health this means ensuring that equal access to healthcare and associated services is guaranteed by the law. This will involve ensuring that all minorities and groups in society have equal access to such services. In addition individuals should be protected from discrimination by the law. States should therefore ensure that responses to epidemic threats meet this principal in providing, as far is possible, equal protection and treatment for all groups in society.

Unfortunately however this would not in itself be enough to minimise the effect of stigmatisation on society. This is because although this measure would prevent the state from acting in a discriminatory fashion or stigmatising individuals through the provision of public services, it would do little to stop stigmatising behaviour between private individuals and groups in society. Groups that form a majority in society can often have stigmatising attitudes towards minority groups of all types. Even though such stigmatising behaviour might not emanate from the state, it can still have such a negative effect (as described above) on individuals in stigmatised groups that if deters them from using public services to the same extent as individuals in non stigmatised groups. The state according to Rawls therefore also has a responsibility also to attempt to minimalise such sources of stigmatisation.

4.3 The Fostering and Involvement of Associations of Stigmatised Groups

Rawls postulated that one possible method of achieving this might be to promote both the establishment of independent associations that represent groups prone to stigmatisation and also contact and dialogue between those groups and those who provide public services (Rawls, 1999). Such organisations are able to provide a secure space for stigmatised individuals to associate with other such individuals. This support can allow otherwise stigmatised individuals to maintain a sense of self respect and resist the stigmatising pressures from elsewhere in society that seek to induce self-loathing and disgust. As discussed above, individuals who maintain ‘self-respect’ are more likely to be able to ignore the negative judgments of other groups in society and to continue to seek their own version of the 'good life' which would *inter alia* include access to the required public goods such as public healthcare. This would avoid or at least ameliorate the negative effects associated with stigmatisation.

The benefits of such a concept have been shown many times in public health situations. A well known example comes from the many associations that were formed by homosexual and bisexual men in the earlier years of the HIV pandemic. *One prominent* example was an AIDS Coalition known as ACT UP that was designed to bring political attention to the plight of gays and lesbians in the on-going HIV/AIDS pandemic (Courtwright 2009). This organisation aimed to make the discussion of such issues not only acceptable amongst affected individuals, but also in society at large. The group also encouraged its members to seek medical attention and not hide through shame of the condition. In a remarkable and symbolic achievement of the progress this group achieved, it managed to turn a symbol of ultimate stigmatisation, the pink triangle, which had been used in Nazi concentration camps, into a symbol of pride for the homosexual community. *Rawls* argued that the presence in society of institutions that treat all individuals equally and the active support and nurturing of groups who advocate on behalf of those who might be marginalised in society would provide the best chance for individuals to maintain their self respect and resist stigmatisating pressures which *inter alia* would allow them to access public health services on a similar basis to society's other members. It is important therefore that those responsible for managing public health information campaigns during the contexts of epidemics liaise as much as possible with groups that are representative of such individuals. This should allow those responsible for such campaigns to discuss the most efficacious methods for communication of health messages in a manner that will reduce stigmatisation for vulnerable groups. Such an approach will allow the idiosyncratic cultural sensitivities of the various groups in question to be taken into account. In addition it will be important before such crises occur to have an adequate knowledge of such groups and who they speak for. This will allow contact to be made quickly in the context of a public health emergency. Such an approach would allow the planers of responses to public health emergencies to be able to avoid potential stigmatisation activities in their responses and also to maximise the potential reach of any programme launched.

4.4Stigmatisation – A Positive and a Negative Role for Public Health Information

This document has already discussed how stigmatising attitudes can take root even where there is no real source of official information that it could be attributed to. Such fears and attitudes seem rather to be an almost instinctual response by individuals when they feel threated and where, through lack of accurate information the threat in question is not well understood. In such situations it seems that individuals make use of the little information they have in order to protect themselves as much as is possible. In the early stages of an outbreak of infectious diseases this will likely include information on the possible geographical origins of the infectious agent in question. In an age where non-official sources of information are numerous and, to a certain extent uncontrollable, individuals will always have access to a wealth of information even if no officially sanctioned information is yet available. The internet and social media has the potential to provide both reliable and unreliable information during an epidemic. During a vacuum in terms of official information such facilities can spread rumour and conjecture widely and almost instantly. In the absence of official information human instinct tends to take over with a likely result that assumptions will be made as to what constitutes a danger in terms of infection. Unfortunately as was seen in the SARS outbreak the first stop for such assumptions is often pre-stigmatised groups that are perceived as already being a risk[19]. The existence of social media networks and the internet in general makes the risk of stigmatisation much greater. This is because such facilities allow stigmatising conjecture and rumour to be spread at a greater speed, to more individuals and over a wider geographic region than might have been the case in times gone by.

This state of affairs provides a clear need for accurate health information to be made public and disseminated as soon as possible. The presence of accurate information may prevent the establishment and dissemination of other unfounded and stigmatising rumours. The availability of further information such as modes of transmission and the potential transmissibility of the infection might allow individuals to make a more rational assessment of the risks involved. Such information would often serve to highlight that the risks of contracting the infectious agent in question from individuals from the minority group in question is not in reality higher than from someone in the general population. This might prevent harmful stigmatisation and its consequential negative effects from occurring to vulnerable communities and economies. Whilst modern networking capabilities pose problems they may also provide solutions in this regard. The use of the same mechanisms that can be used to spread rumour and conjecture can also be harnessed in order to spread accurate information. Indeed such facilities allow a quicker and more extensive spread of information than might otherwise have been the case. This might aid in preventing stigmatisation that may have otherwise occurred as a result of the inability of accurate information to pervade its way through the various communities that exist within societies through traditional media sources. In addition, the existence of social media and other internet communication methods allows novel possibilities of monitoring for medical authorities. Such possibilities may allow medical authorities to quickly identity potentially stigmatising rumours or misinformation that is capable of causing harmful stigmatisation to vulnerable groups or persons. Such knowledge may provide the ability to act by targeting the release of more accurate information designed to dispel any harmful unfounded rumours that may be circulating. Given the development of such technological platforms that is currently underway, it may be valid to conclude that medical authorities have both negative and positive duties with regards preventing stigmatisation in the context of an epidemic. In terms of a negative duty, this entails a responsibility not to unnecessarily to release information that could be of a stigmatising nature to certain groups or individuals. In terms of a positive duty such powers have a duty to quickly provide accurate information (where possible) where such information can prevent the unnecessary stigmatisation of certain groups or individuals.

4.5 Social Contact and Human Health

Strategies that aim to deal with epidemics of infectious disease can use a variety of different methods. These can vary from the distribution of vaccines, to recommending barrier methods, to the distribution of information regarding symptoms and even recommendations on the limitations of social activities in order to reduce transmission rates. Such recommendations could involve avoiding large groups of people, traveling a large distance to see people or avoiding as much as possible contact with certain categories of individuals. The aim of such proposals is to reduce the transmission rates between individuals and thus reduce the number of cases occurring. This can be important in providing breathing space for public health

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[19] Prejudices towards Chinese eating habits were linked to the spread of the disease. See section 24

resources in addition to saving lives. Whilst these are of course valid goals, the pursuit of such goals may come at a price, that being that certain social functions individuals are accustomed to engaging in are prevented. In grave circumstances, during an epidemic of a dangerous disease for example, this may be acceptable and easy to reconcile, it will none the less be important to balance the gains of such an approach against the harm that will be caused. Social contact is important for several reasons, some are connected to the economic activity that such acts entail and their importance to the economy overall.

Social contact is associated not only with individual happiness and contentment but also with human health. Research has shown a clear link between level of social support available to individuals and morbidity and mortality (Uchino et al, 1996). Social contact can also provide an important coping mechanism for those who feel stigmatised. In recent decades this is a topic that has received a considerable amount of attention from researchers (Reblin & Uchino, 2008). Social isolation has been inedited as an increased risk factor for most types of mortality. Social support can be conceptualised into structural components (for example the social infrastructure available including the various networks that allow people to participate socially) and functional (these describe the activities individuals are able to form perform through others e.g. emotional support or favours). Additionally, in recent years research has highlighted the importance of being able to give support (in addition to receiving it). This has shown that individual health is not only improved by receiving support but by the ability of individuals to bestow care on others. In older individuals the ability to still feel 'socially useful' to others has for example been shown to have a beneficial effect on individual health (Grunewald et al 2007). The most common link in terms of health benefits that has been linked to social support is in the area of cardiovascular disease. Social link can therefore play an important role in the preservation of individual health and also in helping individuals live with stigmatisation. Public authorities should once again take such factors into

5. Public Health Campaigns and the Assent of Human Rights Over Medical Ethics

Whilst it may be somewhat universally accepted that public health information campaigns should be examined from an ethical or moral perspective there may disagreement over which approach to use. It has been argued by some that conceptions of bioethics should be applied to potential public health strategies in order to determine their suitability (Gutman & Salmon 2004). Others prefer the use of human rights based principles, where the infringement of individual rights would only be permissible where the situation in question made such action 'proportional (Mann, 1997). This remainder of this document will focus on the application of human rights principles to problems that can arise in epidemic situations. The following paragraphs will attempt to differentiate human rights principles from medical ethics principals and demonstrate why they are better suited for this task.

Contemporary medical ethics represents a collaboration between different theoretical schools of ethical philosophy (Peel, 2005).Medical Ethics in its modern form usually adopts the concept of principal's. This approach was championed by Tom Beauchamp and James Childress. They championed the use of four principles that they claimed represented a combination of the various moral theories accepted throughout the world. The principles are 'respect for autonomy', 'non-malfeasance', 'beneficence' and 'justice'. It was claimed that these principles arose from "considered judgements in the common morality and medical tradition (Beauchamp & Childress, 1994). There is no hierarchy amongst these principles though some would argue that if there was, autonomy would be in the highest position, some going so far as to say that 'autonomy' as a principle is 'first among equals' (Gillon, 2003). Medical ethics have been used by physicians and those providing health interventions for centuries, if not millennia to decide upon the moral acceptability of possible treatments.

Human Rights are designed to provide fundamental protections for individuals that allow them to have as equal as possible a level of participation in society. The Rights contained within human rights instruments are often general, but given their wideranging applicability offer protection for individuals in a wide range of circumstances (Peel, 2005). The effect of Human Rights Instruments is to restrain state power (or force states to act) where it is required in order to protect individual rights. This means that individuals can compel states to desist from certain actions or compel them to take others if those actions are consistent with their individual rights. Human Rights are therefore also applicable with regards to the provision of healthcare, which in most societies the state is seen as having an important responsibility in regulating.

5.1 Differentiating Medical Ethics and Human Rights

Rights with regard to medical treatment can broadly be separated into two areas, moral rights and legal rights. The first describes something which through moral reasoning it can be argued that an individual is entitled to. The second is something which an individual is entitled to as a result of the laws of the society in which an individual lives in. Whilst it is recognised that laws have a moral underpinning it is not always the case that moral rights are enforceable in law. Patients, for example, in hospitals have a moral right to be treated in a polite manner but dot not normally have a legal right to enforce this through their legal system. There are advantages to the use of principals in medical practice. They provide a concise and coherent set of principles that doctors can use when making decisions. The system is easily taught to trainee medical professionals and does not require an advanced prior training in ethical or legal issues. The simplicity of the principals allow them to act as ethical trigger points in situations where individual medical professionals are required to make quick decision in urgent circumstances (Faunce, 2005). This is in contrast to human rights, which to a certain extent, represents a more complex discipline which is usually the domain of experts in the field. Regulators in most jurisdictions have traditionally differentiated the potential application of medical ethics principals and human rights law. There are however undeniable connections between the two systems. One can easily find human rights that are analogous to principles of medical ethics. The principle of autonomy for example is analogous to the right of freedom from inhuman and degrading treatment and the right to not to be arbitrarily detained. The use of medical ethics in medical planning and decision making has however been challenged to a certain extent in recent times by the assent of Human Rights as the principal system by which ethical dillemas are being assessed. The principles found within Human Rights have been used increasingly by legal systems in the past decades to regulate healthcare provision. Human Rights systems have evolved from a 'tradition of moral and political discourse between citizens and the powers which govern. For some, human rights systems are now seen as important means of implementing medical ethics principles. The Australian National University Medical School for example now teaches its students that human rights will, in the course of their careers, become more important in professional regulation than medical ethics (Faunce, 2005).One key practical difference between the two systems is that one (human rights) focuses on the relationship between the state and its citizens and the other (medical ethics is more concerned with a person to person relationship (i.e. between the physician and his or her patient). Another key aspect is the importance given to the notion of benevolence in medical ethics, a concept which is not present in human rights theory.

Medical ethics, though having been refined in modern times can be considered an ancient discipline. Many texts are for example attributed to Hippocrates who lived from 460-380 BC (Peel, 2005). It has accompanied the medical profession throughout the centuries since the ancient Greeks and up to the present time. One can observe that until the 20th century most medical relationships (i.e. those between physician and patient) were largely paternalistic, with the physician often taking decisions in the best interests of the patient. Often the patient would provide very little input into the decision and so would largely place his trust in the doctors opinion. This could be attributed to many different factors. It explains to a certain extent the need for beneficence as a principle in medical ethics, to ensure the good intentions of the physician. The medical professional was held in high esteem and physicians held prominent positions in society. As a consequence, questioning their decisions may have been not socially acceptable or even embarrassing. In addition, patients would have had a poor understanding of the discipline of medical science and thus not have been in a position to question the opinions of their physicians. Such concepts have however changed in more recent times. The Second World War saw physicians that had sworn to uphold ethical principles participate in heinous atrocities. Both the atrocities that were committed during the conflict in general, and those committed more specifically by physicians, gave rise to a change in sentiment whereby a physician’s own beneficence was no longer considered unquestionable. In general the democratic victors of the conflict wanted to support principles that would ensure that modern states could not commit such terrible abuses in the future. This resulted in *inter alia* the Universal Declaration of Human rights which espoused principles that would protect individuals from undue violations of their individual rights by those in power.[20] Further developments based upon these principles continued at the regional and national level. The European Charter of Human Rights for instance is binding upon most European states, the rights contained therein are legally enforceable in most of the signatory states. In the area of medical practice the emphasis shifted from trusting that the doctor always knew what was best for his patient to a situation where individuals were to be regarded as the best arbiter or what exactly was in their own best interests.

In addition, individuals within society began to develop the ability to access types of information (including medical information) that had hitherto been out of reach. This development went hand in hand with the increasingly high level of education which larger groups of western populations had attained. Once can also observe this on a generational basis where younger generations have been shown to have a better understanding of medical terminology than older ones (Thompson & Pledger 1993). The result of these developments was that many patients felt able to conduct their own research into their conditions and, where necessary, question or even refuse their physician’s desired course of treatment. Crucially, human rights instruments provided for this, mandating the use of informed consent before treatments are to be carried out. Whilst medical ethics in its modern form also recognise the concept of autonomy, it co exists in a non-hierarchal fashion with the three other main principles. In this system the concept of beneficence also plays a crucial role where the physician in question is obliged to act only where he has ‘good intentions’. It can be argued that this concept, which is not present in human rights frameworks, represents the old paternalistic framework that existed before the assent of human rights. In this system the beneficence of the physician was the main element in insuring that patients interests were being respected. In human rights instruments however beneficence is not present because it is assumed that the

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[20] See the section in this document concerning human rights for a more in-depth description. The section begins at page 34

patient himself is in the best position to guard his or her own interests through the process of informed consent.

Another factor that should be recognised is that the practice of medicine has changed considerably throughout the ages. In times gone by, physicians would act largely alone, in single one person practices. They would offer their services for financial remuneration to whoever was in need and whoever could pay for them. Modern medicine is a different affair however, with the provision of medicine being organised on a greater scale and often by the state (Rastegar, 2004). Public health campaigns designed to tackle epidemics are one manifestation of this. The cost of modern equipment and medicines would prohibit access for all but the most wealthy individuals. As a consequence, services are provided by much larger organisations (often controlled or regulated by the state) which can utilise the economies of scale that exist through offering such services to the entire population. As a result states must make decisions about which services are provided to individuals and which are not. In doing so there will inevitable winners and losers. The role of the state in such instances is to ensure that the individual rights are respected as much as is possible in the allocation of resources. The state must ensure that if individual rights are to be denied it is only in cases where it is necessary and proportional to secure the rights of others. On this grander scale, systems of human rights are often better placed to adjudicate disputes than systems of medical ethics which are better adapted to dealing with dilemmas involving one or a few individuals. Human rights are therefore particularly useful in in dealing with competing claims by various groups in society that often arise during the deployment of state resources. This could arise during an epidemic for example where various groups demand privileged access to treatment or where one group challenges public health information because they claim that it stigmatises their group. In addition to being more applicable to the large scale situations such as epidemiological strategies which relate to entire groups or whole societies, human rights principals are also recognised as carrying more legal force. Human Rights principles are now routinely used in deliberations by courts in determining outcomes of healthcare disputes in court. The status of medical ethics as being a legally recognised system is much less certain. The following section of this document will therefore for these reasons analyse possible interactions of human rights principles and law with medical responses during an epidemic situations.

6. Human Rights - Relevance to Responses to Outbreaks of Infectious Diseases

The following section of this document will analyse issues of discrimination and stigmatisation in the light of contemporary human rights principles. Human Rights are inherent to all people because as humans they are by their very nature rights holders. These rights create duties for the states in which such individuals live (Gostin & Berkman, 2007). The duties upon such states can be both positive and negative in nature. They may be required to desist from certain actions which infringe upon human rights and, in other cases, to take action in order to secure the human rights of individuals. Human rights principles emanate from numerous sources on the international, the national and the regional level. On the international level the primary sources are the Universal Declaration of Human Rights and two international covenants on human rights: the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). In addition, the UN has created a number of treaties concerning more specific human rights violations in areas such as migration, racial and gender based discrimination and also governing rights of other groups such as children. Each of these contains principles that may be pertinent during the course of an epidemic. As the names of these two treaties suggest, they are intended to cover broadly two different genres of human rights i.e. on the one hand civil and political and on the other economic and social rights. Although by no means a watertight conception it can be broadly be said that the first category outlines negative rights, i.e. where the state generally speaking is required not to do certain things. In this category one can envisage rights such as the freedom from inhuman and degrading treatment and liberty of person. The second category on the other hand is more concerned with instances where the state has to take positive action in order to secure the rights in question. Such rights are often described as second generation rights as they have received much more attention in recent decades that originally was the case (Novogrodsky, 2009). In this category one can find more resource intensive rights such as the right to housing and even the right to health. Rights in both of these categories have a pertinence to public health responses to epidemics. With respect to civil an political rights, this may for example include the right to life, the rights to privacy. Regarding social and economic rights this will most notably include the right to health. Human Rights that are applicable in an epidemic situation can range from those that were intended to apply specifically to such situations (e.g. Article 12 of the UN ICESCR obligates the State to take measures to prevent and control epidemic and endemic diseases), to other that apply by virtue of their general nature (e.g. privacy rights).

6.1 A hierarchy of rights – Civil and Political vs. Social vs Economic Rights

It becomes immediately apparent to those who have a familiarity with human rights issues that the two genres of rights do not carry equal weight in terms of enforceability. This is for several reasons. The most obvious is that the ICESCR has no enforcement mechanism unlike the ICCPR. The role of the UN with regard to the ICESCR is merely to issue reports on compliance of states with the contents of the ICESCR. Another reason is that rights, such as a right to health described in the ICESCR are often not absolute rights but rather present a duty to move in a progressive manner towards the realisation of that right. Such rights therefore provide a duty for states to employ their best efforts to achieve the goal in question. This provides for a certain degree of relativism in terms of what the rights in question actually mean to individuals in different states. This is because a wealthy state will be under a duty to use more resources in the realisation of the right in question than a poor state. A third problem for social and economic rights is that in deciding upon questions of commitment of resources to one project or another states are given a wide margin of appreciation deciding upon what balance to employ between competing demands. Civil and political rights on the other hand are considered to have a hierarchal position, at least in terms of legal enforceability. At the international level, the ICCPR contains mechanisms to allow the admission of complaints on individual cases. These mechanisms allow individuals and NGOs to file complaints concerning potential abuses of political and civil rights. On the regional level, states have agreed treaties such as the European Convention on Human Rights and Fundamental Freedoms and The American Convention on Human Rights. These treaties provide for yet stronger enforcement mechanisms. The ECHR in particular has an extremely powerful enforcement mechanism with a court based in Strasbourg which can decide upon cases in a manner that is binding upon states that are signatories of the convention.[21] The focus of the discussion below will therefore be primarily focused those civil and political rights that are capable of having an impact on a government's response to an epidemic situation. This will include a description of

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[21] The authority for the court is provided under Article 19 of the ECHR

how such rights can be engaged in the context of a pandemic and the potential legal consequences that can ensue. Though the primary focus will be on such civil and political rights, mention will also be made of the right to health, a social and economic right which has also proved to have relevance to the control of infectious disease, particular in the context of the worldwide epidemic of the HIV virus. This following section will be divided into three areas. The first will explore the general principles contained within most human rights instruments and their potential applications in epidemic situations. In most cases the ECHR will be used as illustrative example. The second part will examine how human rights provisions on discrimination are likely to affect strategies designed to counter epidemics whilst the third section will discuss what protection human rights instruments offer against some of the potential stigmatisation issues involved in epidemics as described in the previous section of this document.

The Possibility to Derogate

International law foresees the possibility to derogate from their obligations to respect most human rights in times of national crisis[22]. These may for example include rights connected to privacy or liberty of person. There are some rights that do not allow derogation no matter how grave the crisis in question may be.[23] This includes rights such as the freedom from inhuman and degrading treatment and freedom from slavery. For other rights a declaration of derogation during a time of an national emergency may be possible. In such circumstances state parties to the ECHR for example can take action where the extent of such action is "strictly required by the exigencies of the situation, provided that such measures are not inconsistent with its other obligations under international law.[24]" These requirements mean that states do not have a free hand to violate human rights in times of crisis. This will include even grave epidemics or pandemics. Courts have shown a willingness to prevent action taking place if these criteria are not present.[25] This is important for states that may wish to take action in crises provoked by outbreaks of infectious disease in that they will by no means have a free hand with to act in manners that may infringe upon human rights. Under such circumstances, if challenged in court states will have to show firstly that it was necessary to derogate from its actions under human rights treaties (such as the ECHR) and also that the action it takes under such derogations is proportional.

All EU Member states are also signatories to the European Convention for the Protection of Human Rights and Fundamental Freedoms. Article 15 of the ECHR provides for derogation for Member States from some of their obligations under the Convention "in time of war or other public emergency threatening the life of the nation strictly required by the exigencies of the situation, provided that such measures are not inconsistent with its other obligations under international law." Like the ECHR, Rights under Article 2 (right to life), Articles 3 (prohibition of torture and inhuman and degrading treatment), are non-derrogable. In the Greek case, the former European Commission for Human Rights held that the emergency must be actual or imminent; it must affect the whole nation, the continuance of the organised life of the Community must be threatened; and the crises or danger must be exceptional, in that the normal

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[22] See for example Article 15 of the ECHR which allows derogation from certain ECHR rights in times of national emergency

[23] Under the ECHR, Article 15 for example states are not allowed to derogate from Article 2, except in respect of deaths resulting from lawful acts of war, or from Articles 3, 4 (paragraph 1) and 7.

[24] ECHR, Article 15(1)

[25] In *A v United Kingdom for example*, a Court dismissed a claim that a derogation made by the UK in response to the attacks of September 11 2001 was invalid, but went on to find that measures taken by the United Kingdom under that derogation were disproportionate.

exceptions permitted by the Convention for the maintenance of public safety, health and order are inadequate. Derogations may only last as long as, and only be exercised to the extent required by, the demands of the circumstance. The result of these limitations on derogation however is to ensure that states must consider the applicability of human rights principles even in grave crises such as serious epidemics.

6.2 An International Obligation upon States to Respect Human Rights in Epidemic Situations

In 2005 the World Health Organisation(the WHO), through its World Health Assembly released a revised version of the International Health Regulations (the IHR).[26] The new regulations were the fruit of ten years work attempting to redraft the old regulations in order to make them more suitable for modern needs (Baker & Fidler 2006). Recent instances of infectious disease outbreaks had indeed shown the previous version, adopted in 1959, to be out-dated. The new version was expanded considerably[27] in scope and seeded more powers to the WHO in times of crisis. Amongst these changes a new and much more potent surveillance systems was introduced. For the first time, the IHR recognises the importance of respecting human rights, stating that the implementation of the IHR should be with the full respect for the dignity, human rights and fundamental freedoms of all persons.[28] This is unlike the previous version that was solely concerned with restrictions on trade and not on restrictions of individual rights (Gostin, 2004). In addition to this, some common human rights principles are found throughout the text (Murphy & Whitty, 2009). Article 42 for example states that all health measures must be applied in a non-discriminatory way. Article 23 stresses the need for informed consent stating that State parties should not apply health measures such as vaccination, medical examination or isolation of international travellers without ‘prior express informed consent’ except in circumstances where there is evidence of an ‘imminent public health risk’. The IHR also contains requirements on any limitations that are applied to existing human rights principles in public health emergencies. For the first time the IHR gives the WHO the power declare disease outbreaks based upon information provided by unofficial sources such as non-governmental organisations or individual scientists. There had been calls for the new version of the IHR to require states to avoid, where possible, the stigmatisation of groups, and individuals (Gostin, 2004). This however did not happen; the revised version of the IHR makes no mention of stigmatisation.

The IHR provisions require *inter alia* the application of the least intrusive and invasive medical examination that achieves the public health objective (Articles 17, 23, 31 and 43) and the need for prior express informed consent except in special circumstances (Article 23). States Parties must treat travellers undergoing health measures with respect for their dignity and human rights, and provide certain facilities to minimize their discomfort (Article 32). The Regulations provide some protection as to confidentiality and lawful use of personal data collected under the IHR (Article 45) and introduce a general requirement of transparency and non-discrimination in the application of health measures (Article 42). It becomes quickly apparent however that the IHR’s reference to Human rights is very general and does not

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[26] International Health Regulations (2005), WHA Res 58.3 23 May 2005

[27] The original IHR was applicable only to 3 communicable diseases.

[28] IHR Article 3

provide specific guidance on individual rights or how they should be protected in practice. Given that the IHR obliges states to be prepared for an epidemic situation and that it also obliges respect for human rights in such planning, one can say that states have an obligation to consider human rights implications during planning for a potential epidemic situation under their obligations under the IHR. This includes human rights within the concept of public law preparedness that has been a hallmark of states' disaster preparation since September 2001. Public law legal preparedness refers to the concept that it is also important to have an adequate level of legal preparedness for public health emergency situations (Murphy & Whitty, 2009).This is because if the correct legal framework is not in place at the time the emergency occurs it may not be possible to implement the required response.

The new Regulations were tested during the H1N1 pandemic in 2009. Despite promising practises, it also highlighted weaknesses in the IHR framework, including the dismissal of the IHR principles obligating countries to respect human rights and cause minimal disruption to the international flow of people and goods. Many of the East and Southeast Asian countries due to experiences in the 2003 SARS epidemic reacted extremely strongly, and not always rationally, to the spread of H1N1 influenza. For example, China and Singapore quarantined some travellers based on nationality (particularly Mexicans, Canadians and Americans), regardless of potential exposure to the H1N1 virus. Others were quarantined if they had recently been in Mexico (Katz & Fischer, 2010).

6.3 The Possible Engagement of Human Rights in Epidemic Situations

Strategies designed to tackle outbreaks of infectious disease often curtail individual freedoms. Prominent examples of such rights or freedoms can include the right of privacy of the individual, the right to bodily integrity and also the right to physical liberty. Poverty and communicable diseases also often have a close correlation (Dute, 2004). This provides a need to ensure that vulnerable groups are protected in what can in the worst case scenario represent a situation of a national emergency. Given the context in which they are used, i.e. emergency situations, such campaigns have however often traditionally escaped an intense level of ethical scrutiny. This has however changed in recent times where media attention on such outbreaks and the scenarios designed to deal with them has been more intense. This has accompanied the increased expectation that states should have a high level of preparedness for all types of disasters, ranging from natural disasters to terrorist outrages and including outbreaks of infectious disease. In addition, in recent times marketing communication principles have been used in public health campaigns, intensifying further the need to look at ethical issues in such communication strategy (Guttman & Salmon, 2004). State organisations that engage in such campaigns usually have good intentions – most notably the limitation of the spread of dangerous infectious diseases. Unfortunately however, this aim is often pursued without adequate attention being paid to the problems such public health campaigns can cause. It is important to first identify the harm caused and then proceed to determine if such harms were necessary or could have been avoided. The following part of this document will examine specific human rights that are often engaged in epidemic situations. The power of human rights to prevent discrimination will also be outlined. The HIV/AIDS epidemic has shown that the potential exercise of public health powers and in particular powers of a compulsory nature have the potential to impact upon human rights, most notably individual liberty, physical integrity and privacy (Dute, 2004).

6.4 The Right to Life

The 'Right to Life' one the cornerstone civil and political rights. It is most often concerned with negative duties upon states i.e. the state being bound to avoid taking the life on its citizens unnecessarily.[29] The right to life though has, with the progression of time, become associated with positive duties incumbent upon states. States for example are required to provide adequate resources in terms of security to protect individuals. The UN Commissioner for Human Rights has criticised interpretations of The Right of Life that are too narrow in scope stating that "it would be desirable for state parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics".[30] This represents a very liberal interpretation of the 'right to life' that is by no means universally shared. Despite this the successful application of 'the right to life' in order to secure access to healthcare has been used sporadically in some jurisdictions. ConcerningHIV is *Mendoza & Ors v Ministry of Public* in Ecuador[31] a court has for example held that the right to life encapsulates the right to health (see below). In that case it was stated that the right to life allowed citizens to take legal action in order to compel health authorities to enact appropriate laws to ensure that adequate resources are made available. In India, in the case, *Paschim Banag Khet Samity v State of West Bengal*[32]the right to life has been used to uphold a right to emergency medical treatment. In this case (of which analogous versions have occurred around the world (Byrne, 2005)) an individual could not find a medical facility in his locality that was willing to admit him with the result that he was forced to seek treatment in a private institution. Unfortunately these cases are not the norm. In most jurisdictions and in Europe[33]in general under the (ECHR) a more restrictive view of the right to life with regards to healthcare. Most cases are concerned with issues such as the right to access abortion or the duty of the state to contain or restrict dangerous substances[34] or other hazards.[35] It can generally be sated therefore that the ability of individuals to compel states to provide medical treatment in the context of an epidemic (for example vaccinations or testing) under the principle of 'the right to life' will, in most jurisdictions, be limited.

6.5 The Right to Health

Article 25 of the Universal Declaration of Human rights outlines a 'right to health'. This right was further clarified in article 12 or the ICESCR which recognises "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health." At the European level, article 11 of the European Social

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[29] The state is of course permitted under most conceptions of human rights to take the lives of individuals in order to protect certain rights of other individuals, most notably the right life. A state is there permitted to use lethal force against an individual in order tp protect the lives of other individuals. The ECHR also allows states also to derogate from their obligation under Article 2 in times of war, permitting them to kill enemy combatants. See ECHR Article 15

[30] *CCPR General Comment No. 6 The right to life (art.6) 04/30/1982*

[31] *Mendoza & Ors v Ministry of Public in Ecuador* Resn No 0749-2003-RA (28 Jan 2004)

[32] *Paschim Banag Khet Samity v State of West Bengal* (1996) 4 SCC 37

[33] The Right to Life is found within Article 2 of the European Convention on Human Rights

[34] In Öneryildiz v Turkey for example the EtCHR stated that the state in question had a duty to protect individuals from methane gas explosions.

[35] In Budayeva and others v Russia for example the EtCHR held that the state had an obligation to act to protect individuals from mud slides.

Charter[36] obliges state signatories to take appropriate measures designed to prevent as far as possible epidemic and endemic diseases. This obviously does not imply that states are under an obligation to ensure that all of its citizens are in good health as such an undertaking would not be feasible. The requirements under this article have been described as representing the healthcare duties of compassionate societies towards its individuals (Novogrodsky, 2009). The Committee on Economic and Social Rights (CESR) has clarified that there is a duty upon states in terms of a right by individuals to access services and goods needed to maintain the highest possible standard of health.[37] Essential medicines have been defined by the WHO for example as being those that satisfy the priority healthcare needs of the population. This definition has been used by HIV campaigners around the world to attempt to secure access to life saving anti-retroviral treatment in developing nations around the world. According to the CESR, states have an obligation to provide efficacious and life saving drugs where possible. Where such provision is not possible states have a duty to show that they are moving in the right direction.

Such an obligation may have implications for states during an outbreak of infectious disease. It would likely imply a duty for states to provide life saving medicines or vaccines to individuals if they were available and, if not, to progressively move in that direction. One can imagine, during the context of an outbreak of an infectious disease that access to potentially important medical interventions such as vaccinations and treatments will become a very sensitive issue. In the 2009 outbreak of the H1N1 influenza virus there was for example a notable clamour for access to antiviral drugs such a Tamiflu (Gallagher, 2009). As was the case with Tamiflu, It is likely that at the beginning of such an epidemic, states will not possess sufficient quantities of such drugs (if they exist) to be able to furnish them to the whole population. Under these circumstances the right to health would not translate itself into a requirement to furnish every member of society with the medical intervention in question. Indeed it may be necessary and sensible for states to concentrate limited resources on certain key individuals such as medical personnel and vulnerable groups. Under such circumstances a right to health is more likely to translate itself into real and concrete efforts in time to acquire or produce more of the treatment in question so as to be able to treat the rest of the population as necessary. This for example is what is envisaged in many plans for dealing with a future unknown outbreak of infectious disease.[38] It is therefore, in reality, not likely, given this perceived duty of 'progressive realisation' that that most states will have to directly modify their immediate responses to epidemic outbreaks of infectious disease. Additionally, a lack of a direct enforcement mechanism for this right in international treaties and covenants also blunts the impact of the so-called 'right to health' on any emergency created by a pandemic outbreak. It should be pointed out however that over 100 hundred nations have written an equivalent right to the 'right to health' into their national constitutions of legislation (Kinney, 2001). This includes many developing nations (Byrne, 2008). Chile for example has provided a constitutional right to health since 1925 (Kinney & Clark, 2004). In Argentina 'the right to health' was used by various community groups to obtain the provision of a vaccination against haemorrhagic fever.[39] South Africa has also been a notable innovator in this regard. In developed nations however, there is less official recognition of a right to health in national constitutional law. In such areas innovative use has been made of civil and political rights to take legal action that could otherwise fall under a right to health. This includes claims made under the right to life and the freedom from inhuman or degrading treatment

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[36] Following its revision, the 1996 revised European Social Charter, which came into force in 1999, is gradually replacing the initial 1961 treaty

[37] Committee on Economic and Social Rights, General Comment No. 14

[38] See for example The EU Commissions document 'Strategy for Generic Preparedness Planning Technical guidance on generic preparedness planning for public health emergencies' 2009 12 01

[39] See: Abramovich., V, "Argentina: The Right to Medicines' in Litigating Economic, Social and Cultural Rights: Achievements, Challenges and Strategies" (Geneva: COHRE, 2003

which will be described in the section below. Even in these states however, the notion will still be subject to the same expectation of 'progressive realisation' meaning that government will be allowed a certain room for manoeuvre according to their circumstances.

The Right to information

The right to health is inextricably linked to the right to information. The right to information concerns the availability and dissemination of information through different channels as well as the quality of the information.

A study on the impact of SARS on in the UK and the Netherlands pointed to the absence of crucial information regarding knowledge of the disease and relevant protection measuresin the European mass media, and the failure of receipt of respondents of appropriate and timely information targeted at vulnerable populations. Although information was provided by different UK and Dutch health agencies, including information targeting Chinese community in Chinese, the respondents expressed concerns about the lack of timely and sufficient information. In the absence of Chinese language information on WHO website respondents would rely on less relevant sources (Xinyu Jiang et al, 2006).

During an EU Barometer survey in 2009 a total of three-quarters of interviewees considered themselves informed about the influenza H1N1. Over half felt *well informed* (56%), and a further one-fifth felt *very well informed* (19%). Another one-fifth of EU citizens felt they were *not very well informed* about the swine influenza (21%), while only a small proportion (3%) said they were *not at all informed* about the pandemic influenza H1N1.Over half of the public felt *well or very well informed* about the H1N1 influenza in all the countries researched – with the exception of Lithuania, where the majority of respondents (54%) felt insufficiently informed about this issue. Those not very well informed or not at all informed ranged from 7% (Slovenia) to 46% (Lithuania). 25% were not very well informed or not at all informed in Cyprus, Slovakia, 26% - Bulgaria, Spain, 30-31% - Czech Republic, Romania, Poland, 37% - Estonia, 43% in Latvia, and 47% in Lithuania. (levels of being informed - by age, gender, rural/urban areas, education).[40]

An Assessment Report on EU-wide Pandemic Vaccine Strategies indicates that when asked if patients being administered the H1N1 vaccine received information leaflets in the appropriate language, nearly all of the respondents said yes. Of the 26 respondents, 19 countries reported providing information leaflets to patientsreceiving the H1N1 vaccine, of which 6 explicitly reported that information was alsoprovided in minority/local/appropriate languages. One country wrote that the health careworkers were also informed of the fact that leaflets in other European languages wereavailable on the EMA website. Another country reported that translation services were made available.[41]

In Finland information leaflets and posters on swine flu were made available in official languages Finnish, Swedish, minority language - Saami, and languages widely spoken by migrant groups - Somali, Russian and English.[42] In the United Kingdom information leaflets were made available in 32 languages (English, Amharic, Arabic, Bengali, Chinese (simplified) Chinese (Traditional), Farsi French Gujarati Hindi Krio, Kurdish Kurmanji, Kurdish Sorani, Latvian, Lingala, Luganda, Ndebele, Pashto, Polish, Portuguese, Punjabi Romanian

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[40] European Commission. Flash Eurobarometre, Influenza H1N1, http://ec.europa.eu/public_opinion/flash/fl_287_en.pdf

[41] Assessment Report on EU-wide Pandemic Vaccine Strategieshttp://ec.europa.eu/health/communicable_diseases/docs/assessment_vaccine_en.pdf , p.78

[42] http://www.thl.fi/fi_FI/web/fi/ah1n1v/materiaalipankki/materiaalit_muilla_kielilla

Russian, Shona, Slovak, Somali, Spanish, Swahili, Tamil, Tigrinya, Turkish, Urdu.[43] Different areas in the UK provided leaflets also in other minority languages. In Latvia WHO sponsored posters were available in Latvia, Russian and English.[44] In Spain the Ministry of Health published leaflets in ten languages, including minority languages and most widespread migrant languages -Castilian, Catalan, Basque, Galician, Valencian, English, French, Romanian, Portuguese, and Arabic.[45] In Ireland Irish Health Service Swine Flu produced an information leaflet for the public available in the following languages - English, Irish, Arabic, Chinese, Polish, Russian, French, and Spanish. In the report on "Swine Flu and the Kurdish Community in Manchester" [46] the focus groups demonstrated that despite the effort and resources which the National Health Service devoted to distributing information around swine flu, the messages are not reaching this particular community. Much information which was circulated within the community was received from Kurdish television, broadcast from Kurdistan.

It must however be stated that although there is much anecdotal evidence, research on the lack of information in different languages, absence of language proficiency as a potential barrier in accessing information and help remains scarce. This will need to be addressed in the future.

6.6 Freedom from Torture and Inhuman or Degrading treatment

Though not common or universally accepted, public health strategies, including those designed to deal with epidemic events, might recommend in extreme cases the possibility of compulsory medical procedures such as compulsory testing or vaccination. Such measures have been used in the past, but in recent times have been frowned upon and would seemingly violate the doctrine of informed consent that is now seen as having a primary role in governing patient –doctor relationships. Despite this trend, the possibility for compulsory examination and treatment including vaccination was foreseen in the latest version of the International Health Regulations issued by the IHR.[47] One might however ask whether there is support for the notion that compulsory treatment (i.e. without the patient's consent) is unacceptable under any circumstances. One possible assumption that has been put forward is that any treatment without a patient's consent would be contrary to article 3 of the ECHR which prevents states from engaging in 'inhuman or degrading treatment or punishment' (Murphy & O'Cuinn, 2010), (Mauro, 2009).

Unlike other some of other Articles of the ECHR (e.g. articles 2, 5 and 8), there are no qualifications available under article 3. This means that inhuman and degrading treatment is effectively forbidden outright under the ECHR. Whilst as of yet, there are no cases that have been brought to Strasbourg regarding the compatibility of Article 3 and the use of certain compulsory practices during outbreaks of infectious diseases, there have been useful analogous cases that might provide a useful indication

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[43] Department of Health (2010). Swine flu information sheet for asylum seekers, refugees and other foreign nationals in the UK, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110808

[44] http://www.nmpd.gov.lv/nmpd/arkartas_situacijas/gripas_pandemija/?page=0&doc=348

[45] http://www.informaciongripea.es/descargas.html

[46] Maffia C., Conway S., Swine Flu and the Kurdish Community in Manchester, TS4SE, 2009, http://www.ts4se.org.uk/wp-content/assets/Manchester_Kurdish_Sorani_Swine_Flu_Focus_Groups_Report_September_20091.pdf

[47] International Health Regulations Article 32 allows in appropriate circumstances an according to national law compel individuals to undergo compulsory examination, vaccination or prophylaxis.

as to whether such measures are indeed legal. In attempting to ascertain what the court might conclude if such a case arose one must look at analogous cases in order to form an opinion. In *Herczegfalvy* the court held that, as a general rule, a measure that is a 'therapeutic necessity', can not be regarded as inhuman or degrading. That case however concerned an individual that suffered from mental illness and so did not possess full capacity to give informed consent. One might therefore ask what would be the outcome where the proposed compulsory procedure were to be performed upon individuals that did possess the capacity to consent and did not provide such consent?

In the *Nevmerzhitsky*[48] case, the court considered the case of a Ukrainian prisoner that had engaged in a hunger strike in protest at his conditions of detention. In response to his situation the Ukrainian authorities took the decision to force feed him. The applicant in the case claimed *inter alia* that this amounted to a violation of article 3 of the ECHR. In what could be read of an endorsement of such paternalistic practices the court concluded that the applicants rights had indeed been violated but merely for procedural reasons and not that force feeding *per se* was contrary to article 3. In its reasoning the court highlighted the finding in *Herczegfalvy* that treatment that is carried out as a therapeutic necessity can not be considered in a violation of article 3. In this case though the court concluded that the Ukranian authorities had not provided sufficient proof to show that they had demonstrated that the force-feeding was in this case indeed a therapeutic necessity. *Nevmerzhitsky* appears to render invalid the assumption that the 'therapeutic necessity' reasoning would only apply to cases where individuals do not have the capacity to give consent. Case law at the Strasbourg level would seem therefore to currently still permit forced or compulsory treatment if it can be demonstrated that such treatment is a 'therapeutic necessity'. In Europe forced treatment measures may therefore be permissible for states during epidemic situations. It is important to recognise however that the situation in each country may vary though, with some states not allowing compulsory medical treatment or only allowing such treatment under specific circumstances. In the UK for example courts have considered the permissibility of forced medical treatment in the prominent case of *Burke (Mason & Laurie, 2004)*. This case involved a tetraplegic patient whose wish to have her ventilator switched off was ignored by her doctors. In this case the court stated that medical treatment given without the consent of a patient violates Article 3 and 8 of the ECHR (the prohibition of inhuman and degrading treatment and the respect for private and family life respectively).It should be pointed out that this interpretation of the ECHR is only binding in the UK, and only until a higher UK court of the European Court of Human Rights rules otherwise.

Possible Future revision of Article 3 Jurisprudence

Whilst at present, the ECHR appears to recognise the possibility of forced treatment, even for those who have the capacity to give (or withhold) consent, there are those who feel that a revision of the jurisprudence is likely in future in order to preclude such possibilities(Murphy & O'Cuinn, 2010). Importantly the applicant in *Nevmerzhitsky* did not actually contend that force feeding itself was a violation of article 3 (the right to life), but rather contended that it was in his specific instance because it was not carried out properly a according to the necessary procedures. If cases such as *Burke* should be brought at the Strasbourg level it is difficult to see, given the courts general acceptance of the notion of informed consent and previous comments by the court describing

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[48] Nevmerzhitsky v. Ukraine 5th April 2005 (Application No. 5825/00)

degrading treatment as treatment of an individual that "grossly humiliates him before others or drives hum to act against his will or conscience",that a court will be able to resist drawing a clearer line against forced treatment of individuals capacity[49].

Further supporting evidence for a possible strict respect for the principle of informed consent comes from the case of *X v Denmark*[50], where the court indicated that it felt that a lack of consent to an experimental medical treatment could constitute a violation of an individual's rights under article 3. Although this case does not concern enforced treatment, it appears to be a good indicator of how strongly Strasbourg connects the notion of consent to article 3(Murphy & O'Cuinn, 2010). It is therefore suggested that a challenge before the courts of any mandatory medical procedure which would have the possibility to be enforced, irrelevant of the patient's consent, would be successful, as such treatment would likely constitute inhuman or degrading treatment in all circumstances (that is if the subject concerned had the capacity to give consent). This means that any public health strategies that recommend such action may dubious in terms of their legitimacy under the ECHR.

Limitations of Nevmerzhitsky- Unlikely to Permit Compulsory Vaccination

It important to note that even if the ruling in *Nevmerzhitsky* is not moderated by future judgements of the EtCHR there is doubt that it would allow all procedures deemed as being beneficial in the case of a an epidemic. This is because *Nevmerzhitsky* and *Herczegfalvy* before it, stated that treatment could not be deemed inhuman or degrading if it was a therapeutic necessity. The concept of a therapeutic necessity appears to refer to the patient upon which the medical procedure in question is to be carried out upon. This would not seem to include procedures that are not likely to be beneficial to the individual in question but which may be of a benefit to the wider society. This may particularly apply to the issue of vaccination where it may be impossible to demonstrate that it is a therapeutic necessity to vaccinate a single patient. Often the benefits of vaccination come from the concept of herd immunity whereby enough members of a society are vaccinated against an infectious agent to hinder its transmission through the community. In such instances it may be difficult or impossible to show that the procedure is indeed a necessity as far as one individual patient is concerned. In such instances an individual patient might argue that his or her individual behaviour does not make it likely that he will contract the infection in question and therefore the vaccination is, from his or her point of view unnecessary. Given this it is questionable whether procedures such as compulsory mass vaccinations could survive a legal challenge by individuals under article 3 of the ECHR. On the other hand, part of a strategy to contain an epidemic may involve compulsory treatment of those who are infected. The treatment of individuals who are infected could be a 'therapeutic necessity' for the individual concerned and also of a potential benefit to the wider society as it would reduce the chance of further transmission. Unlike mass vaccinations, instances such as these would likely fall under the concept of 'therapeutic necessity described in *Nevmerzhitsky* and *Herczegfalvy*.

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[49] Denmark, Norway, Sweden and the Netherlands v. Greece ('The Greek Case') (1969) 12 YB at 186
[50] X v Denmark DR 282 (1983)

Consent in Medical Procedures and Its Applicability to Public Health Information Campaigns

The foregoing analysis has described the centrality of the notion of informed consent to the issues of medical treatment and the freedom from inhuman and degrading treatment. Some have raised the applicability of the notion of informed consent towards public health information campaigns. Such an approach would seem to attempt to analogise such public health information campaigns to actual medical procedures themselves. As human rights principles began to be applied to the medical world they gave rise to the development of requirements such as consent and later informed consent to the potential medical procedures (Wicks 2001). Under most western human rights frameworks in all but a few limited circumstances it would be forbidden for a doctor or other health professional to perform a medical procedure on a individual without securing his or her informed consent first.

It is however possible to question whether such principles should or even can be attributed to public health information campaigns. One can imagine or point to examples where public health campaigns might be the subject of objection by individuals or groups of people within society. Individuals for example might object to being categorised as part of an at risk group and being grouped with others for whom they feel little connection or affinity. Relatively healthy elderly people might for example feel unfairly castigated in a health campaign that warned that individuals of retirement age and above were at an increased risk of more serious complications than younger people. In addition, groups of people may object to their group being identified in a manner that they feel is less than favourable. This might for example apply to groups of minorities who for one reason or another are identified as being more susceptible to the spread of an agent responsible for infectious disease. Such a group might for example feel that this might make their overall position in society more difficult. The difference between such situations and most medical interventions performed on individual people is the scale of their impact. In most cases a medical intervention performed on an individual will affect solely that individual. An blood transfusion on one individual will not effect the health of others. Thus in deciding whether such a procedure should be carried out the interests of the patient involved are the primary concern. Modern notions of human rights presuppose that the patient is (if adequately informed about his situation) is in the best position to decide whether such a procedure should be carried out. This is because it is that individual who is in the best position to decide whether the supposed benefits that the procedure will bring are worth the potential costs that the procedure may involve (recovery time, economic costs, compromised religious beliefs etc). Given that most of these issues are matters that concern only the individual patient concerned it is not acceptable that a medical professional rather than the patient themselves should be able to decide that the patient concerned should undergo the procedure concerned.[51]

With public health information campaigns however the amount of individuals who will be effected by the action in question is much greater. This is because often such a campaign will be targeted at all or a large portion of society. Such campaigns may not have positive or negative effects on one individual or even on a group of individuals but more likely upon a whole society. It is therefore questionable whether the same principles concerning human rights and individual consent could apply to public information health campaigns that apply to not one but potentially large groups of people. In such instances an individual might well be in a good position to judge the potentially negative aspects that will be created for him/her as a result of a public health information campaign but will not be in a position to adequately assess the benefits to other individual members of society and even society as a whole. Not only are individuals

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[51] This might therefore be a useful place to employ the concepts described earlier in this paper regarding communication and liaison with associations composed of stigmatised individuals. This was based on ideas by Rawls and Courtwright. See page 30

unlikely to be able to assess such positive effects or quantify them correctly, it is also unlikely that such individuals will be able to weigh these positive effects for society as a whole against the negative effects that will occur for them in a proportionate manner. These issues provide valid reasons as to why individuals should not generally be able to withhold their consent and thereby block or alter public health information campaigns that are designed to apply to the whole of society. This discourse my seem entirely logical to those tasked with producing public health information campaigns and represents a form of reasoning synonymous with utility based ethical theories upon which most of such campaigns have been based.

6.7 The Right to Liberty and Security of Person

In extreme circumstances public authorities might recommend the isolation or quarantine of individuals thought to be suffering from incidences of infectious disease in the early stages of a potential pandemic. Such action has been taken in the recent past, notably in the SARS crisis, where such measures have been attributed with success in limiting the spread of the disease. There, the use of quarantine measures was deemed as being of significant importance in the effort to halt the spread of the disease. The World Health Organisation declared that such efforts were responsible for preventing an enlarged spread of SARS and allowing transmission of the disease to be halted within 4 months (Parashar & Anderson, 2004).In Canada for instance wide scale use of such measures was made with considerable intrusion upon personal liberties, with for instance, 2000 asymptomatic individuals there having been quarantined there.[52] During the SARS outbreak health authorities set various criteria that could be used in determining if a person was to be quarantined including: persons that stayed within a radius of two meters of a probable case, persons who came into contact with body fluids of a probable case and persons who stayed in the same room as a suspected case (Dute, 2004). The aim of such measures are to protect the health of society by isolating infected or potentially infected individuals so that they can not spread the infectious agent further. Such actions therefore aim to protect society as a whole by restricting the rights of certain affected individuals. In a modern democracy the detention of individuals who have not been accused or convicted or any criminal activity ranks as one of the most serious possible impositions on individual rights. Article 5 of the ECHR states that individuals are entitled to the Right of Liberty and Security of Person unless specific cases which are provided for by law exist. One such possible instance is where the action in question is to 'prevent the spreading of infectious diseases'.

This power of involuntary detention or quarantine was examined by the European Court of Human Rights in *Enhorn v Sweden*.[53] That case involved measures taken in Sweden to detain a HIV positive individual. The individual in question had already been identified as being responsible for infecting other people with the virus. As a consequence Mr Enhorn had been presented with a list of conditions such as informing all sexual partners about his condition, informing medical staff that would treat him, that he take adequate precautions during sex, that he limit his alcohol intake and that he should have regular consultations with his doctor. When it became clear that Mr. Enhorn was not meeting all of these conditions an order was made that he be detained in isolation for a period of three months. Mr Enhorn escaped this detention several times and was subsequently re-detained. After appeals against this before the Swedish courts Mr

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[52] The Nuffield Council on Bioethics , Public Health: Ethical Issues (NCOB 2007) 52. Officers at borders or ports were given the power to ask individuals to undergo medical examination and if necessary to detain the individual concerned for up to 20 days, a period corresponding the maximum incubation period for SARS.

[53] Enhorn v Sweeden [2005] ECHR 56529/00

Enhorn took this matter to the European Court of Human Rights in Strasbourg. The Strasbourg court found that his detention had been illegal. It based the reasoning of its decision on two important legal principles connected to article 5. In procedural terms, the court was concerned that the measure in question be prescribed by law and in substantial terms that the measure in question be proportional and not open to possibility of arbitrary imposition (See Commentary, 2006). Regarding the procedural requirements of such measures the court stated that the measures taken must be provided for in law (i.e. exist in legislation) and that the application of such measures should be foreseeable. This means that any law should be well enough detailed to allow an individual to foresee how it might be applied in various circumstances. Regarding the substantive requirements of article 5, the court reasoned that for an individual to be detained because they are suffering from infectious diseases it must be demonstrated that the person is indeed suffering from the disease in question and that the spread of the disease poses a risk for public safety. Furthermore, the detention should be the last possible resort in order to prevent the disease in question from spreading. In Mr. Enhorn's instance, the Strasbourg court felt that this last condition had not been met i.e. that his detention was not the last possible resort in his case. This was because there was not sufficient evidence in this case that less severe methods had even been considered.

The importance of Enhorn for Public Health Information Campaigns

Enhorn is limited to an analysis of an application of Article 5 to healthcare practices, that is in cases where individuals are placed in quarantine or isolation in order to further prevent the spread of infectious disease. Therefore its application to public health approaches in the context of an epidemic would be limited only to instances where such action would be part of such a plan. *Enhorn* means that, in Europe at least public health strategies, will have to adhere to the requirements elicited in *Enhorn* if they involve the potential use of quarantine or isolation techniques. Firstly, procedurally speaking, any plans should only envisage the use of such techniques where they clearly exist in the law of the state in question. As described by the court in *Enhorn* the provision for such techniques in national law must be detailed enough so that individuals can reasonably foresee their use. If such laws are not in place or not sufficiently detailed any public health strategy that foresees the use of such techniques as being necessary must offer advice on the promulgation of such laws. Secondly, with regard to the substantive requirements, it will be important for public health information campaigns that wish to advocate the use of such isolation methods in certain circumstances to emphasise the necessity of demonstrating that all alternative (and less onerous) measures should be considered first before grave measures (such as isolation or quaranteen) can be considered warranted. For the relevant healthcare professionals to be justified in deciding that such measure are necessary they must be able to demonstrate that the measures in question are necessary and proportionate, taking into account the negative affects on the rights on the individuals concerned and positive effects for society as whole. Healthcare professionals should also be advised that they should be able to demonstrate in such instances that less intrusive measures would not be suitable under prevailing circumstances. It is important that such procedures are met in order to ensure that strategies that form part of public health information campaigns are open to legal challenge.

6.8 The Right to Private and Family Life

In the ECHR, article 8 has two principle paragraphs. The first describes the rights that the article protects i.e. those associated with private and family life. The second contains potential reasons that might justify infringement of these rights. One such reason is the protection of public health. If the rights in the first paragraph are engaged by an action that it is necessary in a democratic society and in accordance with the law it may be permissible if the aim of the action is *inter alia* to protect public health. In deciding upon whether measures are indeed necessary in a democratic society,courts such as the European Court of Human Rights (the EtCHR) make use of a 'proportionality test'. This would involve an assessment of whether any infringement of an individual's rights was proportionate in order to protect the human rights of other members of society. Unless these criteria are met any breach of the rights protected by article 8 will not be permitted. article 8 of the ECHR is of a potentially enormous application. This is because there are any enormous variety of actions (and also inactions) that a state can engage in which can impact on an individual's ability to enjoy his or her family life as he or she might so desire. The following paragraphs of this document attempt to illustrate some of the manners in which Article 8 can be engaged in the medical context. The right to private life covers for example the right to develop one's own personality, in addition to creating and maintaining relationships with others.[54] This ability to form relationships is not restricted to small and intimate groups of individuals such as family or partners but is understood to include anability for an individual to form relationships with wider circles of human beings that might live in society. As will be seen this can be in areas where there are both positive and negative duties upon states i.e. duties to act and duties not to interfere.[55]

Obligations to Make Certain Treatments Available

The rights contained in article 8 of the ECHR are not only negative, in that they envisage restraining the activity of the state but can also be positive in that can also envisage the state taking certain steps to protect individual private and family life.[56] This means that for example a failure to provide adequate healthcare can also violate an individual's rights under article 8. This might be for example because the necessary treatment would allow the individual to live at home and maintain a close link with their family. The civil and political 'right to a private and family life' can therefore complement the social and economic 'right to health'. As described above however the benefit of making use of a civil and political right is that they are usually easier to enforce upon states than their social and economic counterparts. It is important to note however that the European court of Human Rights has afforded a 'significant margin of appreciation' to states in deciding which treatments they are to fund and which they are not.[57] The court has stated that whilst article 8 could be used to give voice to complaints regarding public funding and treatment procedures it accepted that it is the states themselves that are often in the best position to decide how best to achieve the balance between the various competing needs for healthcare that exist within a society.

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[54] *Niemietz v. Germany*, 72/1991/324/396
[55] Stierna -v- Finland (1994) (134)
[56] Passannante v Italy, 01/07/1998
[57] See for example Valentina Pentiacova and others v Moldova (2005)

Confidentiality

Individuals have a general right to expect confidentiality regarding their medical status. The EtCHR has recognised that the right to respect for private and family life includes a right to respect for medical information.[58] The EtCHR has also clearly linked the concept of data protection to that of privacy and of being important to the enjoyment of a private and family life. Only in instances where there is an overriding requirement in the public interest can such a requirement be breached.[59] Data protection requirements for medical data are governed primarily by a directive (Directive 95/46/EC), that has been transposed into law in each member state. This regime also governs medical data[60] where such data is classified as being sensitive in nature and therefore attracts the highest level of protection. Data protection requirements in Europe for medical data may be respected *inter alia* by the use of anonymised data, or where the data subject gives their express consent for the use of non-anomymised. The use of non-anomonous data however may be required in the context of an epidemic. Such data may, under the European Data Protection regime, be processed without individual consent if doing so would be in the public interest. This however requires that legislation governing such processing is in place before hand[61]. This may be important in the context of epidemics where centralised bodies at the national and international level are trying to gather information on the severity and rate of transmission of an infectious agent on the ground. In addition the use of personal information that has not been anonymised can be useful in tracing the origin of an infection in a particular area. Indeed, surveillance has become an important approach of modern communicable disease detection and follow-up (Dute, 2004). Such surveillance has been defined as the "systematic collection, analysis and interpretation of health data essential to the planning, implementation and evaluation of public health practice closely integrated with the dissemination of these data to those who need to know" (Thanker & Berkelman, 1998). Access to such information may be of crucial importance in allowing responses to an epidemic to be planned or modified as needed. In the initial phases of an epidemic detailed information on individuals who have become infected and their lifestyles will be needed in order to discern the likely rate of transmissibility of the virus. It is conceivable that some patients may not want information about themselves, the location and their lifestyle to be passed by their doctors to external bodies. In the case of *Z v Finland* the court outlined that only in certain instances where it is clearly in the public interest can such details be revealed without individual consent. Problems have a arisen in certain states where medical data is not adequately protected. This can give rise to stigmatisation which can *inter alia* mean that individual fail to seek treatment as a response. In Russia for example it has been argued that a lack of protection for personal medical data has led to the stigmatisation and consequent treatment avoidance of HIV individuals there (Gage, 2008). Adequate preparation will be important for states in ensuring that they are compliant with data protection requirements and their wider duties to protect the private and family lives of individuals. In terms of data protection this will involve a anonymising all personal data where possible. Where this is not possible it will be important to have pre drafted legislation in place allowing for such processing in the public interest. This is a process that will obviously need to be in place before an epidemic takes place. Such legislation will have to be sufficiently precise to comply with the legal requirement of foreseeability but also to allow sufficient flexibility to deal with future unknown and unexpected pandemics.

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[58] M.S. v Sweden 1997 313, 333

[59] Z v Finland (1997) This case concerned the revelation during a trial that a victim was HIV positive. The court content that it was important that legal systems respect the confidentiality of patient medical data in order to ensure that patients could continue to have confidence in their respective medical systems.

[60] M.S. v Sweden 1997 313, 333

[61] Directive 95/46/EC Article 8(4), *S and Marper v United Kingdom* [2008] ECHR 1581

What is necessary is a democratic society?

In order for an action that engages individuals rights (such as those described in the above) to be permissible it must be necessary in a democratic society. As with any legal phrasing it is important to look at what exactly this means and then apply it to the context in question, in this case an epidemic. It will be extremely important for those in charge of a public health response to a pandemic to act in compliance with the necessity requirements or their actions are likely to be prone to legal challenges by individuals that perceive themselves to be negatively affected. The concept of necessity excludes measures that are simply 'desirable' or useful. On the contrary necessity implies that the selected measure is the least harmful. The existence of less severe methods (in terms of infringement of personal rights) that could also be used to achieve the aim in question would render a proposal unnecessary.

In deciding whether an alleged interference is justified the state has the burden of proof to show that its action was proportionate. Any interference must correspond to a pressing social need and such interferences must proportionate to the aim used. In deciding upon what is proportionate one must decide whether a measure in question is necessary for achieving a legitimate aim and if so, whether it fairly balances the rights of the individuals with those of the community (Curtice, 2009). The European Court of Human Rights has applied a test in deciding whether the concept of proportionality has been met. In this test the court first identifies the aim of the proposed measure corresponds to another convention right (than the one that is being engaged). The court will then determine if the proposed measure corresponds to a pressing social need and then will proceed to determine if achieving this aim is proportionate given the proposed violation of the concerned individual rights under article 8 of the convention. In addition, the court will look to whether the reasons given by the authorities for the decided course of action are relevant and sufficient. Proposed measures should be as restricted as is possible in their effect and application and also exist in conjunction within sufficient safeguards within the law to prevent abuse. The aim of this test is to prevent the state from acting disproportionately, even in order to achieve a legitimate aim. In general this means that the more grave the inference with individual rights the greater the efforts that will be needed in order to justify such a measure

States therefore face an extremely delicate balancing act during outbreaks of dangerous infectious disease. A response that is too minimalist could fail to limit the potential health threat, resulting in increased morbidity and mortality for the population and large scale economic damage. A response that is too maximalist could result also in economic damage, in the estrangement of entire communities, the lost of trust in public services and possibly even social order problems (Tarantola et al, 2009). The existence of legal requirements such as necessity and proportionality reflect this. The disadvantage of such requirements is however that they place a certain burden on medical authorities at a time when they will be under a high level of stress due to an unfolding epidemic situation. Such authorities may need to demonstrate that the measures they have opted for are necessity that is to say there are no other less severe methods available. It may be difficult to demonstrate this in the early phases of an epidemic when little may be known about the infectious agent in question.

6.9 The Right of Non Discrimination

EU Member States are signatories to many legal instruments that guarantee the right of access to health care free from racial or ethnic discrimination. The principles of non-discrimination and equal protection irrespective of race, ethnicity, social or other status are enshrined in several international conventions, the International Covenant on Civil and Political Rights (ICCPR)[62], the International Covenant on Economic and Social Rights (ICESCR), and the Convention on the Elimination of All Forms of Racial Discrimination (CERD). As with the other rights discussed above the most important however is once again the ECHR given its potential for providing legally enforceable remedies. Whilst Article 14 of the ECHR[63] provides an important guarantee against discrimination for numerous categories of individuals, it does not however provide any stand alone rights or a general right against discrimination.[64]Article 14 is designed in such a way that it is only activated when another convention right is engaged. This means that in order to use article 14, individuals must be presented with a situation that engages another right such as the freedom of private and family life or the right of liberty and security of person. If such a situation presents itself individuals can not be denied their rights under the convention because they belong to one of the groups in question. In the context of public health provision this could include the withholding of treatment from certain groups because of safety or efficacy concerns. This right could also be used by individuals who that are denied access to other (non-healthcare related) public services because of their health status. This could conceivably occur where individuals have become (or have been) infected during a pandemic. The EtCHR has stated that for discrimination to occur, members of one of these groups must be treated differently from other persons in an analogous situation without and objective and reasonable justification.[65] If an applicant can show that he has been treated differently because he belongs to a group that is caught by article 14, the state in question must prove that it can objectively justify the treatment of the individual concerned.[66] In order to provide reasonable and objective justification the state in question must show that there is a reasonable relationship of proportionality between the means employed and the aim that is sort.[67] In deciding this, states can be said to enjoy a margin of appreciation according to their own particular circumstances. This means that the court will allow a certain room of maneuver for states in assessing their own individual situation. This reflects the reality that individual states are often in a better position to assess the reality of a given situation than a distant court can retrospectively. Such a margin is reduced however where the case in question involves a group that is vulnerable and already prone to suffer discrimination. In such instances states will have to provide more significant reasons for their actions and

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[62] In accordance with Article 2(1) of the ICCPR, Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Article 26 of the ICCPR prohibits discrimination on any ground with regard to policy or law. Article 2(2) of the ICESCR declares: The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

[63] Article 14 reads as follows The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

[64] Kiyutin v Russia No. 2700/10 10 March 2011 Para 53

[65] D.H. and Others v. The Czech Republic [GC] no. 57325/00 (2007) and Burden v. The United Kingdom [GC] no. 13378/05 (2008)

[66] Chasshnou and Others v. France [nos. 25088/94, 283331/95 and 28443/95

[67] Kiyutin v Russia No. 2700/10 10 March 2011 Para 53

the resulting discrimination that occurs. This acts to protect vulnerable minorities and groups that have historically been the subject of discrimination from suffering further abuse. In *Kiyutin* the court for example deemed individuals that are HIV positive as forming such a group given the discrimination that such individuals have suffered in recent times.[68]

In *Kiyutin* the court concluded that Russian government's decision to refuse the claimant a residence permit on the grounds that he was HIV positive was not valid. This is because it could not demonstrate that the violation of the individuals Article 8 entitlement to a private and family life (with his wife and child in Russia) was reasonable and objectively justified in order to protect public health. In that instance recourse could not be made by the Russian state to the potential economic costs that such an individual would pose because under Russian law non-Russian nationals are not entitled to treatment under Russia's healthcare system and must pay for such treatment privately.

7. Human Rights and Stigmatisation – Alien Concepts?

Human Rights Instruments no doubt have an important role to play in protecting individual rights in the domain of healthcare. They prevent the state from detaining individuals, from forcibly treating or vaccinating individuals in all but the most demanding of circumstances.[69] Human Rights also prevent states from providing services in a discriminatory manner i.e. favouring one group over another in its provision of a treatment. This provides an important protection for minorities that they will not be excluded from the same level of healthcare treatment that is available to other groups in society solely by virtue that they belong to the minority in question. Discrimination in the provision of medical services or information can have damaging consequences for groups and individuals both in terms of preventing the spread of the infectious disease in question and also other negative health based and social outcomes. Human Rights instruments therefore have an important role to play in regulating the execution of such vital activities.

Human Rights Instruments therefore provide an important protection against discrimination for vulnerable and stigmatised groups. We havealready discussed however in the description of problems associated with stigmatisation described above that stigmatisation can bring about various negative effects, even where stigmatised individuals are not the result of direct discrimination. This can be through indirect structural discrimination for example that is often difficult to prevent, through health care avoidance by those that are stigmatised, through the negative health effects of long term stress, through perceived physician bias and even through a reduced motivation to strive for the necessary goods of a successful life.[70] Given this, one might therefore ask can human rights instruments also prevent stigmatisation in the first place? The prevention of such stigmatisation would therefore not only avoid the negative effects described here but also the chances of discrimination that exist by virtue of being part of a stigmatised group.

Unfortunately, however Human Rights instruments do not seem to be engineered to provide the same protection against stigmatisation as they do for the protection of individual rights and for protection

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[68] The court noted that widespread ignorance over the mode of transmission of the virus in its first years had been responsible for creating a climate of fear which led to discrimination of individuals that were HIV positive. See Kiyutin v Russia No. 2700/10 10 March 2011 Para 64

[69] See page 37and onwards for a description of the limitations human rights place upon public health strategies in times of vaccination.

[70] See page 15 for a description of some of the negative affects that has been associated with stigmatisation.

against discrimination. A useful recent case which provided a interesting example of how the European Court of Human Rights considers the relationship between individual rights, discrimination and stigmatisation is that of *Kiyutin v Russia*.[71] This case concerned an application by an Uzbek national for a residence permit in Russia where he had a wife and child. The individual concerned was refused because he was HIV positive. In examining whether his treatment was acceptable under the ECHR, the court looked as Russia's obligations under the ECHR in the light of the pronouncements of various international bodies concerning the application of human rights principles in cases of HIV and also with regards to the stigma and its effect on the treating the condition. The claimant's denial of a residence permit was based on Russian law that requires that foreign nationals resident in Russia should be denied residence and deported if they are HIV positive.[72] This is in contrast to Russian nationals that, under the same law, are entitled to free treatment for HIV.

The court pointed (paragraph 27) to a declaration by the UN General assembly[73] which recognised that the issue of stigma for those who are HIV+ can have negative effects in efforts designed to prevent the spread of the virus and treat those infected with it.[74] Interestingly the court in *Kiyutin* declared that the "full realisation' of human rights principles would reduce stigma, allowing benefits in terms of prevention and treatment. In order to ensure this, states should ensure *inter alia* access to 'education, in heritance, employment, healthcare, social and health services".

Which human rights might therefore be relevant for individuals with infectious diseases? In *Kiyutin* the court made use Article 14 of the ECHR which is represents an obligation by states not to discriminate in ensuring that human rights are respected amongst various categories of individuals. Article 14 prohibits discrimination based on "sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status". Whilst health status is not explicitly mentioned in this list, there is reason, as the court in *Kiyutin* observed, to believe that the potential category of 'other status' contained with article 14 includes individuals who may be discriminated against because of their health status. The court highlighted that the UN Commission on Human Rights has for instance stated[75] its conviction that 'other groups' should include individuals suffering from HIV.[76]

The court in *Kiyutin* also recognized that (paragraph 33) with respect to HIV, the behaviors that are responsible for its transmission are nearly always within the context of private activities i.e. sexual activities or intravenous drug use. As a result prevention requires voluntary acts of individuals such as having safer sex or using clean needles, actions which occur out of public spaces. The court reasoned that it was therefore difficult to compel individuals to take such preventative measures. In addition, it recognized that restriction measures against individual with HIV can run counter to prevention efforts as such efforts often stigmatize individuals resulting in negative healthcare seeking affects like those that have been described elsewhere in this document. The consequence of such restrictive measures might therefore be a reduction in the amount of individuals seeking treatment for the condition. Furthermore, the court reasoned that unnecessary measures against foreigners would create the perception amongst individuals of a state that

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[71] Kiyutin v Russia No. 2700/10 10 March 2011

[72] HIV Prevention Act (no. 38-FZ of 30 March 1995) Section 4

[73] United Nations General Assembly Declaration of Commitment on HIV/aids (Resolution S-26-2)

[74] See also page 16 of this document where negatives health outcomes from stigmatisation of those with HIV was discussed.

[75] United Nations Commission on Human Rights – Resolution no. 19995/44 The Protection of human rights in the context of HIV and AIDS

[76] The Committee on Economic and Social Rights has also recommended that the term 'other status' contained within the equivalent article of the United Nations Covenant on Economic and Social Rights should also include individuals with adverse health statuses such as HIV. See General Comment on Non-Discrimination No.20

conditions such as HIV were a foreign problem and would reduce the likelihood that they would take appropriate measures for prevention of infection. In its deliberations the court was clearly influenced by recommendations made by the Joint UN Programme on HIV/AIDS and the International Organization for Migration.[77] This communication emphasized that restrictions on the international movement of individuals could only be for valid reasons such as the protection of public health or for important economic reasons. With regard to public health the nature of HIV means that individuals who are infected with the virus are not a threat to the health of the public. Individuals can easily take precautions unlike with certain other conditions such as influenza) which would ensure that they would not become infected with the disease. There is therefore no valid argument in cases such as *Kiyutin* for refusing entry of HIV positive individuals for the protection of public health[78]. With regards economic reasons the court accepted that there may be a justification for refusing individuals with conditions such as HIV if such individuals were likely to be a burden on the health system present in the state in question. Such an assessment would however have to be made on an individualised basis, taking into account the economic benefits which the individual in question would provide to the state in question as a resident. Consideration, the court stated should also be given to any specific reasons of a humanitarian nature justifying authorization for a person to enter or stay in another territory.

7.1 Kiyutin's Approach on Stigmatisation

The *Kiyutin* case provides an interesting insight into how the European Court of Rights views the relationship between stigmatization issues and human rights. The first thing of note is that the court does not attempt to engage in an in-depth analysis of what exactly constitutes stigmatization. On the contrary, there is no attempt to define the concept. The court simply referred to stigma in a manner that implied that it thought there was no need to define the concept. This is unlike the academic literature on stigmatization which, as has been described above is extremely varied and rich it its discussion and even in debating what exactly a definition of stigmatisaiton could be.

Whilst not attempting to specify what exactly stigmatisation is, the court made it clear that stigmatization is something that should be avoided for individuals that have health issues such as HIV. The court was particularly concerned with the negative affects that stigmatization can have on the prevention and treatment of an infectious disease such as HIV.The court was particularly influenced by statements from the Joint United Nations programme on HIV/ Aids and the International Organisation for Migration on the problems that stigmatisation poses for prevention. The court was of the opinion that the protection of human rights and individual freedoms was essential in order to prevent stigmatization of those with conditions such as HIV. This can be seen as taking a very different approach from academics such as Link and Phelan who see that stigmatization can give rise to discrimination but does not have to do so (Link & Phelan, 2001). On the contrary, they see discrimination as something that usually flows from stigmatization and not necessarily the other way around. For example, under their framework individuals can view others, such as those perceived to be at a higher rate of infectious disease as being of a lower status than themselves but may not treat them differently *per se* or act in any other overtly discriminatory manner. It is

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77 UNAIDS/IOM statement on HIV/aids-related travel restrictions, June 2004

78 Such advice has also been issued by the office for the UN High Commissioner for Human Rights, see: The International Guidelines on HIV/aids and Human Rights (2006 consolidated version)

only when an individual decides to act upon such beliefs and treat the individual in a different manner that he is partaking in a discriminatory act. Thus discrimination can occur of stigmatized individuals, but stigmatization can occur without discrimination and even when discrimination is prima facie prevented. There seems therefore to be a 'chicken and egg' style difference in the way in which the ErtCHR and academics such as Link and Phelan view the conceptual relationship between stigmatization and discrimination.

The court's judgment also made no reference to the various negative effects that occur to stigmatized individuals even if there is no discrimination against them. These can result from a sense of reduced self worth or even self loathing (Courtwright 2009). Such effects include a reduced motivation to seek preventative healthcare or medical treatment, direct negative physical effects associated with a chronic stress response and even a reduced motivation to secure the essential goods required for a successful life. Each of these negative affects can be present even if no discrimination occurs. Given this one might take issue with the courts assessment that the protection of individual rights and fundamental freedoms is sufficient in itself to prevent the negative effects that are associated with stigmatization. This is because it is possible to have negative effects from stigmatization even where no discrimination is occurring with regards to the protection of individual and fundamental rights of individuals by states.

One possible interpretation of this difference in views could be that the ECHR, as interpreted by the EtCHR, is designed to protect individual rights but not designed to prevent stigmatization. Whilst protecting individual rights as recognized in the ECHR might prevent a worsening of a pre-existing situation of stigmatisation it will not prevent the stigmatisation of certain groups in the first place. There appears therefore to be no general right to be free of stigmatisation or acts that might potentially stigmatise individuals. There are several important factors in support of this. Stigmatisation can arise through numerous mechanisms, not all of which require human or fundamental rights of individuals to be violated. It can arise through common cultural perception, something which the state may have played no active role in creating, or perhaps certain events of a geopolitical nature of which the state was powerless to prevent. Stigmatistion in other situations may be an almost natural human reaction to an event such as the outbreak of an infectious disease amongst a certain sub segment of the population (Hsin Yang et al, 2007). Whilst it is possible the state might be able to reduce the effects of stigmatization in time with education programs or other measures to support the stigmatized community it is not feasibly possible for the state in question to prevent such stigmatization from occurring in the first place. On other occasions, the state might, through its actions be unintentionally responsible for the creation or reinforcement of stigmatization whilst it was in performing some other necessary act. This might for instance be the case when a state makes health information available to the public. Public authorities might for example inform the public that certain behavioral activities make the transmission of an infectious agent more likely. Whilst this act might result in the stigmatisation of individuals who whish to pursue such an activities, the act of informing the population may have been entirely responsible so that individuals can, if they wish, avoid the behavior in question and the associated risks of a negative health outcome that may be associated with it. In such situations it would be very difficult to argue that states should not inform the public of such information and keep it in a state of ignorance in order to avoid the stigmatisation of certain groups of the population. One could argue therefore that individuals would have little or no recourse to stop governments from such actions under the ECHR and other prominent human rights instruments.

Another reading of the court's pronouncement in *Kiyutin* however might suggest that the court will look at the engagement of individual rights in the context of stigmaitsation in order to decide whether interference of such rights is necessary. This could for example be where an individual alleges a public health information campaign has produced a situation where it is impossible for the individual concerned to enjoy his right to a private or family life as he would wish. This could occur where the information released concerned a small minority, perhaps one which was already the subject of stigmatization. If public health information were in such instances to highlight such individuals as being at risk it might be possible that this would have severe consequences for such individuals in attempting to pursue their own and their family's' lives in the general community. This could result from the difficulty for them in securing important goods such as housing, employment or education or even health care in the community. In such an instance a court might feel that individual rights under Article 8 had been engaged. Under such circumstances it would proceed in a manner has been identified above to examine if such measures were indeed necessary in a democratic society to protect public health and so as to confirm that there had not been unnecessary or disproportionate discrimination against the group concerned according to article 14. In doing so a court would have to look at the circumstances in question and decide firstly if individual rights were actually engaged. If they were, the court would then be tasked with deciding whether if under the circumstance the action it had taken was necessary i.e. that no other less severe course of action could have been taken and that the measures taken were proportional to the ends sort i.e. the protection of public health. If less severe methods were available in terms of the infringement of individual rights, or the methods chosen i.e. the information released and the manner in which it was communicated were not proportionate given aims pursued in releasing the information then a court may decide that such an act is in violation of individual rights under the convention according to articles 8 and articles 14.

A court would likely take several factors into account in making a decision. First of all the overall aim of the health information campaign would be assessed, including the severity of threat from the infectious disease and its potential consequences if such information were not to be released. This would then have to be weighed against the negative consequences for an individual complainant. Here the court could take into account the effect that any stigmatization occurred would have on an individual's rights under article 8. Any negative effects caused to an individual's private or family life would have to be judged necessary and proportionate. In addition, the court would assess whether adequate reasons had been provided by the state in question for its decision to highlight a certain group as being at increased risk of infection of transmission of an infectious disease. This would again entail the demonstration that it was both necessary and proportionate to highlight the group in question and the consequences that would occur if such action was taken. As the court stated in *Kiyutin* if the minority or group in question is already vulnerable to stigmatisaiton the state in question would be required to demonstrate extremely compelling reasons for its actions.

In reality however, it is, according to the authors' opinion, unlikely that a court would, in most cases find public health information campaigns to be a violation of individual rights as a result of the stigmatization that might ensue for certain number of individuals. This is because it is likely that most campaigns will be seen as pursing a legitimate aim i.e. the protection of public health in a necessary and proportionate manner. Public health campaigns are often necessary because without information it is often impossible for individuals to have the requisite knowledge to take steps to protect themselves against an outbreak of infectious disease. If a such an disease, is for one reason or another, more prevalent in a certain community then it is often the members of such a community that are in most need of such information. Targeting a community most at risk may be most effective method of helping not only members of the general public, but member of that community itself. It would therefore probably be possible to make the argument that withholding such information would cause potentially serious harmful effects on individuals in such groups including negative health consequences and possibly even death. Providing the public with the necessary information arguably protects individual rights such as the right to life. This is often even more true for the targeted minority which may be at greater risk of negative health outcomes. It likely therefore that one could argue that not informing individuals of the necessary facts during a situation might constitute an infringement of individual's right to life as described in Article 2. This will also be the case for individuals within a target group who may be in a position to profit from such information. This would likely provide adequate necessity for a public health campaign, even if there was a risk that a certain level of stigmatization might emerge as an undesired consequence. Even where some individual's rights under article 8 are potentially engaged the protection of other individual's rights under article 2 is likely to render the publication of such information proportionate as it has been accepted by the ECHR that article 2 rights i.e. 'the right to life' occupy a higher hierarchical position that article 8 rights.

Where an infectious disease in not likely to seriously threaten individual lives the state in question may have to do more to demonstrate that the engagement of individual rights under article 8 (that may arise due to excessive stigmatization) is necessary and proportionate. This is because such engagement would no longer rest upon arguments that such information was being emitted in order to save lives but rather to prevent non lethal infections. Such an action may still be permissible under the exception allowed in article 8 for the protection of public health or also for the protection of vital economic interests, but will be subject to the need to show that the measures taken are necessary and proportionate as described above.

In summary, there may thus be some scope under the ECHR to guard against potential stigmatization as a result of public health campaigns. This may however in reality be limited by several factors. Firstly it will likely be necessary to demonstrate such stigmatization will result in a right under the ECHR being breached. Additionally it will need to be shown than the measures taken that resulted in such breaches were not necessary and proportionate to the aims of the measure in question. Where as is often the case in public health campaigns the aim is to prevent mortality or serious morbidity is likely that in most cases the stigmatization that occurred as result would not be deemed sufficient to render the measures taken disproportionate. In addition, given that the provision of information is at the least interventionist end of a long possible list of potential medical interventions it is not likely that such measures would not be seen as necessary. This is immediately obvious when one considers other alternatives such as quarantine, compulsory vaccination, and compulsory testing or travel control measures. It is therefore not likely that in most cases another less severe course of action could be found for the provision of medical information.

Concise Summary of Key Points Likely to be Relevant During the Context of an Epidemic.

1. Stigmatisation can bring about a range of negative effects that can have consequences during an epidemic and afterwards. These effects which can occur even in the absence of overt discrimination include;

- **Health care avoidance;**
- **Cardiovascular health problems as a response of long term stress;**
- **A lack of motivation to seek the necessary goods in life;**
- **Physician Bias.**

2. Some individuals are more likely than others to suffer stigmatization during the context of an epidemic. These include;

- **Medical Professionals;**
- **Pre-stigmatised groups e.g. the poor, homeless, immigrants, the old, individuals with conditions that result in a reduced immunity;**
- **Ethnic minorities;**
- **Individuals associated with the perceived geographic origin of the outbreak in question;**
- **Individuals that become infected;**
- **Animal Origins of an Infectious Agent;**
- **Individuals that are to be vaccinated;**

3. Stigmatisation can be reduced by ensuring that discriminatory practices are not permitted and by fostering communication with associations or representatives of groups that have the potential to be stigmatised. Communication between public health response planners and the representatives of such groups should be facilitated in advance of an epidemic.

4. Human Rights Principles will be important to bear in mind during an epidemic response. Such principals come from a variety of sources at the international, regional and international levels. Such principals include;

- **Specific obligations upon states to act in the context of an epidemic;**
- **The right to health (often conceived of as a right to access healthcare);**
- **The right to life;**
- **The freedom from inhuman and degrading treatment (important in the context of compulsory treatments);**
- **The right of liberty and security of person (important in the context of the potential use of quarantine);**
- **The right to a family and private life (important requirements concerning patient data);**
- **Prohibitions on discrimination.**

5. Whilst human rights principals are useful protecting the fundamental rights of individuals in the context of an epidemic they are not able to completely prevent stigmatization during an epidemic. This is because the self-loathing needed for stigmatisation to exist can arise even where the state has itself done nothing to foster such a feeling.

CONCLUSIONS AND RECOMMENDATIONS

Stigmatisation is an ancient concept, one that humans as a species may have evolved as a social behaviour under certain circumstances. Modern academic study of the concept began in the second half of the twentieth century with the seminal work of Goffman. In the decades since, sociologists and psychologists have attempted to refine the conceptual underpinning and definition of stigmatisation in order to take into account phenomena that have been observed in different circumstances. In the contexts of epidemics important aspects to take into account include that stigmatisation often involves individuals with readily identifiable traits (such as individuals belonging to minorities), that such traits can often be linked characteristics that are given negative moral connotations and that individuals most susceptible to stigma are those who occupy inferior positions in relationships of power. In the context of epidemics, groups that are prone to stigmatisation include those groups that have a perceived connection with the geographic origin of the outbreak in question, members of the medical profession, those who are part of pre-stigmatised groups, those who have connections to perceived animal origins of an outbreak and those individuals who actually become infected themselves.

Those vested with responsibility for planning public health responses to epidemic situations should take into account the existence of such individuals and their susceptibility to stigmatisation when planning their actions. This is because stigmatisation should be avoided not only because of moral issues that may be involved but also because stigmatisation can create or augment certain very deleterious effects that can have negative consequences for both the individuals involved and also for society as a whole. These include the possibility of healthcare avoidance behaviours, something which can have very serious consequences during an epidemic and is capable of worsening its course. As has also been observed amongst various stigmatised groups, stigmatisation can also result in a decreased motivation to seek the goods required to prosper in life. These include aspects not only in the area of healthcare, but also in areas such as education an employment. Stigmatisation can have a negative effect of the ability of such individuals to obtain such goods on an equal basis to other members of society and thus reduced in a reduced quality (and even longevity) of life. In addition, long-term stigmatisation is capable of producing serious direct effects on the health of individuals in the form of worsened cardiovascular health. Given the serious nature of these negative effects the planners of public health responses to epidemics should seek to, where possible avoid, or at least minimise, creating new problems of this type or entrenching those that pre-exist amongst groups that are already stigmatised.

In order to avoid unnecessary stigmatisation, there are two principal strategies available to those who plan public health responses. The first is to ensure that the provision of healthcare services is made on an equal basis to all, irrelevant of society's opinion on their moral status. This acts to prevent vertical discrimination by the state of those who are stigmatised,by avoidingthat such individuals are left out of the provision of key medical services during an epidemic. However as has been described briefly above, the active act of discrimination does not need to be present in order for stigmatisation and its negative effects to occur. One key act of discrimination is a sense of self-loathing that can result from the perceived negative perceptions of one's peers' views on their own existence. Such negative perceptions can establish themselves even in the absence of any overt discrimination by the state or other actors in society. In order to reduce such a sense of self-loathing it will be necessary, during the context of epidemics, for public health authorities to engage with groups or associations that represent those who are stigmatised in society. This will allow public health campaigns to take into consideration the sensitivity of such groups and also allow stigmatised groups to reinforce their own sense of self worth, allowing them to resist the stigmatising pressures from other members of society. Such an approach has shown itself to be very efficacious in the reduction of stigmatisation for those individuals who are HIV positive. The engagement of such groups could be optimised not only through the identification of such groups (where possible) long in advance of an epidemic but also through constructive dialogue in the planning of a response to a potential epidemic.

Human Rights have a valuable role to play in the regulation of responses to epidemic situations. Human Rights systems have been rising in prominence in recent decades and have begun to challenge the traditional role of medical ethics as the dominant system for deciding upon the provision of care in many settings. The ability of human rights systems to help balancing competing claims by various rights holders upon limited resources makes them suitable in assessing public health strategies in the contexts of an epidemic. States are obliged though both international law and their own national law to respect a variety of human rights principals. At the international level, whilst the state may be bound to respecting each treaty, the availability of a reliable enforcement mechanism may depend according to the treaty in question. This can be seen immediately by comparing the lack of an enforcement mechanism available under the ICESR (and to a certain extent the ICCPR) with the potent mechanism available under the regional ECHR. It is of crucial importance for the planners of public health responses to epidemic situations to ensure that their potential strategies are compliant with such principals. This is not only to ensure moral consistency, but also to prevent such strategies being halted by legal obstacles at what could be critical junctures during the course of an epidemic. Such problems could result in graver epidemics than otherwise might have been the case and a consequent increase in both morbidity and mortality. The Human Rights Principals that are applicable during epidemic situations vary, from very precise duties upon states to act to prevent and deal with epidemics to other more general principals that will inevitably apply in such contexts. These include principals associated with both civil and political rights and also social and economic rights. Important principles to consider are *inter alia* the right to life, the right to health, freedom from inhuman or degrading treatment, rights of physical freedom, the right to a private and family life and also freedoms against discrimination.

The Right to Life concerns primarily negative duties upon states not to take the lives of individuals (except in exceptional circumstances like war). Whilst there is some case law in some states which interprets the right to life as providing a positive duty upon states to provide healthcare this is limited, with most interpretations, including the ECHR foreseeing a limited role for the right for live in providing for a positive duty upon states to provide healthcare facilities.

A positive duty to provide healthcare finds for itself more a natural home within ‘the right to health’ which is located in various international treaties. This social end economic right foresees a duty upon states to provide healthcare for individuals in need of such services. This right has been used by groups of individuals, most notably in the developing world, to secure access to vital healthcare services such as vaccinations or antiretroviral therapy. The use of such a right comes with several caveats however. Most notable is the relative nature of such a right – it provides not absolute duty to provide a certain level of healthcare but a duty to move in the right direction as much as available resources permit. Another problem is the discretion given to the state (especially in the west) to make its own value judgements where competing claims occur upon resources. The social and economic nature of the right also weakens its effectiveness given that its enforceability under international treaties is usually limited (though many states do actually have an equivalent principal written into their national law). It is therefore not likely that individuals will be able to make use of the right to health (unless it is a constitutional principle in their state’s constitution) to compel states to make vaccinations, testing and treatments available where the state, has in the context of an epidemic, deemed such treatments not to be cost effective. This is important, as many states, in their preparedness plans for a serious epidemic, will envisage targeting certain valuable or vulnerable groups for vaccination. Indeed it may even be impossible for public health authorities to provide treatment, such as vaccinations, to anyone who might want such an intervention as the availability of such treatments may be limited (or not even exist) at the time an epidemic strikes. It would be wise however for a state to base such prioritisation on objective and clearly demonstrable grounds so that it can be shown that such prioritisation is in line with its obligation under the notion of a right to health under international law.

The right to freedom from inhuman and degrading treatment provides important guarantees to individuals regarding their bodily integrity. In the area of medical practice the right has been closely linked to the concept of informed consent. This concept, which arose in the decades following the Second World War requires such consent to be present before treatment can be carried out upon individuals. This notion however does not sit easily with the potential use of several draconian procedures in the context of a pandemic. These include quarantine, compulsory testing, compulsory treatment and also compulsory vaccination. Such powers are recognised at national level by many states in their national law and also at international level in *inter alia* the International Health Regulations. Case law under the ECHR has however indicated that such treatments are not necessarily precluded. The case of *Herczegfalvy* demonstrated that states may carry out treatments on individuals without their consent if such individuals do not have the capacity to consent and the treatment in question is indeed a medical necessity. The *Nevmerzhitsky* case even permitted the compulsory treatment of a prisoner who did possess the capacity to consent and had refused the treatment in question. Despite this surprisingly permissive ruling, the court did indicate that states must demonstrate there are no other less stringent courses of action available. It has been suggested however that the future may herald changes in the way the European Court of Human rights views this matter. The notion of informed consent is becoming ever more deeply imbedded and the idea that individuals can be subjected to treatments without their consent is certainly at odds with this. Given this, it could be viewed as possible that future cases brought before the EtCHR may view this matter differently. Public health authorities should therefore be cautious in relying upon the use of compulsory treatment measures, being able, where they do, to clearly demonstrate that other, less severe, courses of action were not available.

Engagement with the right to liberty and security of person is also a significant possibility during a serious epidemic. The right envisages freedom for individuals from arbitrary detention. There is obvious scope for conflict with such a right with techniques such as quarantine which have been employed for many years during serious epidemics. This right was considered extensively by the EtCHR in the context of public health powers in the case of *Enhorn*. In that case the court ruled that the detention of individuals under public health powers may be permissible but only if certain strict conditions are met. Firstly, such detention must be necessary and proportional, meaning that the detention or quarantine must actually serve a purpose and must be the least severe method available in order to achieve that purpose. In addition, the court highlighted that in order for such power to be valid they must already exist within legislation and be outlined in sufficient detail that its potential use be foreseeable. These will represent important requirements for the planners of public health responses to epidemics. If the potential use of such powers is envisaged it will be important in the context of legal preparedness to ensure that powers exist already exist in legislation before an epidemic arises. This may entail a review of pre-existing powers and their alteration as may be necessary. International or regional organisations such as the UN or the EU may also have a role in ensuring that their constituent members have updated their legislation as may be necessary and informing them if this is not the case. In addition, those tasked with implementing potential quarantine measures during epidemic situations should be prepared to be able to justify both the necessity and proportionality of the actions should the need arise through legal challenge.

The right to a private and family life will also represent an important concept for public health planners to consider. In the context of healthcare it has been linked to both positive and negative obligations. In terms of positive obligations, a state can be required to act where such action is likely to protect an individual's private or family life. Negative duties envisage however an obligation upon states to desist from acts that may prevent individuals from realising this aim. Like the right to liberty and security of person this right is usually not perceived of as an absolute right. It can be engaged by states in order to secure the protection of public health, but only where once again the use of the methods in question meet the concepts of necessity and proportionality. Given the wide ranging embrace of this right, it can have implications in a variety of ways for those tasked with planning public health responses to an epidemics. With regards to positive obligations in terms of the provision of medical services the court has stated that whilst this right could be used to give voice to complaints regarding public funding and treatment procedures it accepted that it is the states themselves that are often in the best position to decide how best to achieve the balance between the various competing needs for healthcare that exist within a society. A more important role for this right is likely in the area of confidentiality of individual data during a medical emergency. The EtCHR has also clearly linked the concept of data protection to that of privacy and of being important to the enjoyment of a private and family life. In Europe the responsible regime for the protection of personal data is the data protection framework. This regime also governs medical data where such data is classified as being sensitive in nature and therefore attracts the highest level of protection. The data protection regime provides important requirements which public health planners should consider. Such requirements may be respected in several ways. The most simple is the use respected *inter alia* by the use of anonymised data. Another possible method is relying upon the data subject to give their express consent for the use of non-anomynised data. However, the use of non-anomonous data however may be required in the context of an epidemic especially in the initial stages where there may be a need to gather data on the properties of a novel infectious agent. Such data may be processed without individual consent if doing so would be in the public interest. This however requires that legislation governing such processing is in place before hand. In *Z v Finland* the court outlined that only in certain instances where it is clearly in the public interest can such details be revealed without individual consent. Adequate preparation will be important for states in ensuring that they are compliant with data protection requirements and their wider duties to protect the private and family lives of individuals. In terms of data protection this will involve a anonymising all personal data where possible. Where this is not possible it will be important to have pre drafted legislation in place allowing for such processing in the public interest. This is a process that will obviously need to be in place before an epidemic takes place. Such legislation will have to be sufficiently precise to comply with the legal requirement of foreseeability but also to allow sufficient flexibility to deal with future unknown and unexpected pandemics.

The right to non-discrimination is not a stand alone right. Rather it can only be engaged in conjunction with another right. This means that in order to use this right, individuals must be presented with a situation that engages another right (e.g. the freedom of private and family life or the right of liberty and security of person). If such a situation presents itself individuals can not be denied their rights under the convention because they belong to one of the groups in question. This right of non discrimination applied to a range of groups such as race, ethnicity and religion and, as been more recently accepted to those who have a different health status (e.g. those who are HIV positive). Discrimination occurs where members of one of these groups are treated differently from other persons in an analogous situation without an objective and reasonable justification. This can provide an important protection for individuals who suffer from health conditions in ensuring that they are not unnecessarily discriminated against. In the context of public health provision this could include the withholding of treatment from certain groups because of safety or efficacy concerns. This right could also be used by individuals who that are denied access to other (non-healthcare related) public services because of their health status. This could conceivably occur where individuals have become (or have been) infected during a pandemic. If states take action which *prima facie* discriminates against individuals because of the health status, they must demonstrate that such action was, once again, both necessary and proportional.

Human Rights Instruments instrument provide important protection against discrimination for vulnerable and stigmatised groups. Stigmatisation can however, by its very nature, result in various negative effects, even where stigmatised individuals are not the result of direct discrimination. This can be through indirect structural discrimination for example that is often difficult to prevent, through health care avoidance by those that are stigmatised, through the negative health effects of long term stress, through perceived physician bias and even through a reduced motivation to strive for the necessary goods of a successful life. There is some doubt as to whether human rights instruments have the ability to prevent such a situation from arising in the first place.Human Rights instruments do not seem to be engineered to provide the same protection against stigmatisation as they do for the protection of individual rights and for protection against discrimination. This problem was highlighted in the recentECHR case of *Kiyutin,*where the court declared that the “full realisation’ of human rights principles would reduce stigma, allowing benefits in terms of prevention and treatment. In order to ensure this, states should ensure *inter alia* access to ‘education, in heritance, employment, healthcare, social and health services.” Thiscase provides an interesting insight into how the European Court of Rights views the relationship between stigmatization issues and human rights. Whilst not attempting to specify what exactly stigmatization is, the court made it clear that stigmatization is something that should be avoided for individuals that have health issues such as HIV. The court was of the opinion that the protection of human rights and individual freedoms was essential in order to prevent stigmatization of those with such conditions.This can be seen as taking a very different approach from academics who have found that stigmatization can give rise to discrimination but does not have to do so. Such a view sees discrimination as something that usually flows from stigmatization and not necessarily the other way around. Thus discrimination can occur of stigmatized individuals, but stigmatization can occur without discrimination and even when discrimination is prima facie prevented. There seems therefore to be a ‘chicken and egg’ style difference in the way in which the ErtCHR and academics such as Link and Phelan view the conceptual relationship between stigmatization and discrimination. The court’s judgment also made no reference to the various negative effects that occur to stigmatized individuals even if there is no discrimination against them. Given this, one might take issue with the courts assessment that the protection of individual rights and fundamental freedoms is sufficient in itself to fully prevent the negative effects that are associated with stigmatization. This is because it is possible to have negative effects from stigmatization even where no discrimination is occurring with regards to the protection of individual and fundamental rights of individuals by states.

Whilst there may thus be some scope under the ECHR to guard against potential stigmatization as a result of public health campaigns during an epidemic, this may however in reality be limited by several factors. Firstly it will likely be necessary to demonstrate such stigmatization will result in a right under the ECHR being breached. Additionally it will need to be shown than the measures taken that resulted in such breaches were not necessary and proportionate to the aims of the measure in question. Where as is often the case in public health campaigns the aim is to prevent mortality or serious morbidity is likely that in most cases the stigmatization that occurred as result would not be deemed sufficient to render the measures taken disproportionate. In addition, given that the provision of information is at the least interventionist end of a long possible list of potential medical interventions it is not likely that such measures would not be seen as necessary. This is immediately obvious when one considers other alternatives such as quarantine, compulsory vaccination, and compulsory testing or travel control measures. It is therefore not likely that in most cases another less severe course of action could be found for the provision of medical information. Individuals that feel that they have been stigmatized by public health campaigns may therefore find that unless one of their fundamental rights has been engaged that they have little recourse under human rights instruments.

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