



# T3.4

## Report on Ethical, Legal and Political Implications (of the New Framework Model)

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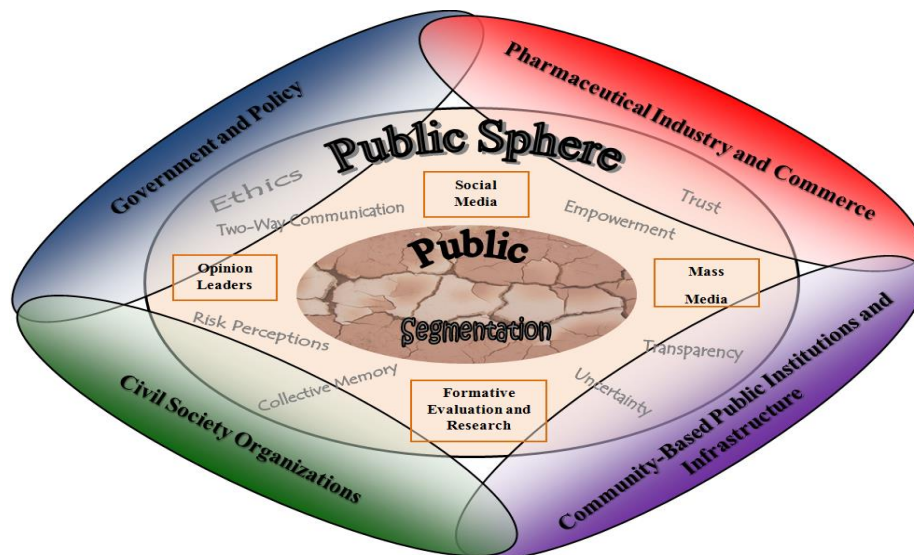
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## A Brief Description of the New Framework Model

The new communications model was presented in Deliverable 3.1 of the Tell ME Project, entitled “New Framework Model” for outbreak communication. It represents a central aim of the TELL ME project, to design a framework model designed for use by public health authorities in the event of an influenza pandemic. Its content was based on extensive research carried out in earlier phases of the project into the successes and failures of previous strategies used to respond to pandemics and, most notably the H1N1 pandemic of 2009. Then, despite the best efforts of public health authorities, reduced levels of vaccine uptake of different groups across various European countries were observed. The gap between the goals and the results of the media campaigns also led to the so-called “boomerang effect”, with segments of the public expressing distrust in the world health system, which it saw as mired in conflicts of interest (Cohen & Carter, 2010). This resulted in the public's noncompliance with the vaccination campaign and a crisis of trust between the public and international organizations and governments. Work on this project revealed the deficit of theoretical and applied knowledge in the area of risk communication and public inclusion through social media.

In order to address these problems the New Framework Model envisages a different approach whereby the public (i.e. the end targets of communicative effort) are placed at the center of efforts, and placed in a more dynamic position where they will be able to interact with public health agencies through community representativeness and stakeholders. This represents a departure from more traditional and linear ‘top down’ models of communication in which the final message was designed by public health authorities and distributed to a public that was conceived of as a relatively homogeneous unit. The New Framework Model recognizes the existence of a much more homogeneous public in terms of a target audience, including members of the medical profession. In addition, through the use of stakeholders and community representatives the new framework model foresees a much more dynamic two-way communication process where messages are distributed and altered according to feedback, before, during and after an epidemic. Such a set-up allows important information to be gathered concerning the efficacy of particular communication strategies long before a pandemic would arise. In addition, it would allow important lessons to be learned for subsequent pandemics.

Fig.1 A Representation of the New Framework Model taken From D3.1



## Executive Summary

This document aims to highlight prominent legal, ethical and political issues that will surround the use of the TELL ME NEW Framework Model (the NFM) which is described above. In doing so it will build upon, and incorporate the knowledge and findings already generated in the TELL ME project, in particular deliverable T1.6 on Human Rights, Stigmatization and Risk of Discrimination Against Specific Population Segments and Target Groups (Deliverable 1.6). The aim will be to apply the knowledge already generated in the first part of the project to the NFM, which has been developed since. The aim of the NFM was to develop a new model for pandemic communication that was less focused on a hierarchical and linear approach, as has been common in the past, and more focused on the mediation of the message and the dichotomy between sender and addressee as being of central importance (see Deliverable 3.2). In doing so, a primary focus of the NFM was to foster a high level of public and stakeholder engagement in each of the planning, the pandemic and the post pandemic phases. This would involve a shift away from traditional top down models towards a model that focused on the engagement of various groups of stakeholders, each of which interacts with the public in its own manner. The NFM, unlike previous models, is accordingly not based on a hierarchic, linear structure and incorporates the active participation of a range of non-public health bodies that are capable of representing a range of possible interests in society, and each capable of communication with a section of the public in a unique manner. Such stakeholders can represent diverse groups and interests ranging from the pharmaceutical sector, to the groups representing medical professionals and even groups representing certain sections of the population e.g. ethnic minorities. In addition, the NFM involves interaction at all stages with important figures, groups and organizations active in the area of mass media, social media and various opinion leaders. The organization of public health communication activities in such a manner raises numerous issues of the type this document is concerned with. In particular, these include:

### International Obligations and the NFM

Legal obligations that may pertain to the NFM can be split into various categories. The first relate to obligations upon states that exist in international law. In terms of the use of the NFM, the most relevant is the International Health Regulations, created by the World Health Organization. The bulk of these regulations relate to issues not directly applicable to the NFM such as the collection and organization of

information, reporting obligations and potential restrictions (in terms of travelers and airports etc.). However, other requirements of the IHR do seem relevant towards to NFM. In particular, aspects related to the ‘core preparedness’ of states for epidemic and pandemics would seem to relate to the type of activities envisaged in the NFM. The WHO confirmed in a recent document that building a state’s core capacities to a sufficient level requires establishing a system of communications that involves a multilevel engagement of various stakeholders. In addition, such engagement should *take* into account “*social, religious, cultural, political and economic aspects*”. Furthermore, the WHO reasons that such a core capacity requires identifying and establishing contacts with such stakeholders before any crisis occurs in order to maximize effectiveness. The implementation of the NFM would accordingly appear consistent with such obligations. In particular, the NFM’s emphasis of diverse stakeholder engagement and upon pre and post pandemic preparation appears to meet the type of efforts envisaged by the WHO in terms of meeting core requirements.

*The Consequences of the Non-Engagement of Important Systems of Law Designed to Protect Individuals Who Suffer Negative Consequences*

Health communication campaigns are, in addition to positive effects, able to create stigmatizing atmospheres that may be conducive to discrimination for others.<sup>1</sup> As a consequence it is important to consider the potential of individuals to use legal frameworks to restrain public health bodies where their activities (including in the context of the NFM) may be able to create such problems. Systems of administrative laws in many states represent one of the most important legal mechanisms for individuals to challenge activities of public bodies and civil servants that may affect them negatively. Such legal frameworks place important limitations on the actions of public bodies in three ways. They ensure that public officials act within the legal authority, that they adhere to important requirements of form (often associated with good governance) and that they comply with important substantive legal principals e.g. constitutional or other provisions relating to human rights. Importantly however, it would appear that most systems of administrative law fail to recognize the type of informational act that the NFM primarily envisages as an ‘administrative act’. This is because such acts are generally not seen as being capable of affecting individual legal rights. As a consequence, it is unlikely that individuals in most jurisdictions will be able to challenge acts under the NFM under administrative law in the courts. This leaves individuals to a large extent unable to protect themselves from any negative consequences that may occur as a result of such informational acts, including possible stigmatization or being subject to the creation of an atmosphere that is conducive to discrimination. As a result, public health officials are able to act with a relatively free hand in composing public health messages in the manner in which they see fit (i.e. adapting where necessary to new forms of communication and social media) and engaging those stakeholders deemed to be advantageous. One potential disadvantage however is that public officials involved in the co-ordination of public health campaigns (such as envisaged in the NFM) will face less pressure to implement measures generally associated with good governance that are normally a requirement of administrative law. This includes obligations of prior announcement, of consultation, a duty to give reasons for decisions and a duty to review decisions subsequently. Given that such requirements are not merely bureaucratic obstacles but are associated with good governance, the possibility that they can simply be neglected is concerning. As a consequence, those involved in the execution of a public health campaign should, where possible, consider

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<sup>1</sup> These factors were discussed at length in TELL ME deliverable 1.6

utilizing such practices, even were they are not obliged.

The lack of potential engagement by legal systems, together with acts that are primarily informational in nature, is further demonstrated by the doubt concerning the applicability of important human rights principals. This has been exemplified by the European Court of Human Rights which thus far has never found stigmatizing or insulting information releases by themselves to be in violation of an individual's human rights. In addition, the court has reasoned that statements by themselves can not be considered discriminatory. In reaching such conclusions the court has also been influenced by the concept that informational acts are not, in most cases capable of harming the legal rights of most individuals.

#### The Potential Application of Data Protection and Freedom of Information Laws to the NFM

Despite the lack of general engagement with important legal systems (as typified by administrative law), public health communication programs (including the NFM) are subject to some more focused legal frameworks. These notably include rules of protection of individual privacy (and most notably data protection) and also freedom of Information laws (FOI). The first of these is relevant because the NFM foresees the use of potential data mining operations that may allow communications to be targeted on an individual level. The use of such personal data raises important legal issues in Europe, especially if such data would refer to sensitive aspects such a health, ethnicity or race. If use of such data is indeed made, it will have to be done so in compliance with important principals of data protection, including data minimization and the existence of a legitimate ground for processing. This latter aspect will present particular problems for the large-scale collection of personal data for data mining processes. This is because, the particular grounds most likely to be applicable for the NFM is 'consent' (explicit consent if sensitive data such as health data is involved). It is difficult to see how the requirements for consent to be valid can be met (particularly where explicit consent for the use of sensitive data is concerned) where data is taken *en masse* from online media and social networking platforms. In particular, it is difficult to see how the generalized consent practices used by such networks will allow such data to be acquired by public health authorities in a way that would meet data protection rules. One possible way to avoid such difficulties is to use anonymized data. Whilst through data mining this could still allow aggregate non-personalized queries to be performed, it would of course render the data set less useful and would not permit personalized data mining as envisaged in the NFM.

The second area of importance, i.e. FOI Laws, is important because it allows individuals and organizations in society to request many kinds of information from public authorities. Given that public authorities will still play a prominent role in the NFM, this means that private parties will be able to request information that may be held by public health planners but which they had not intended would be made public. The potency of such laws and their potential effects on the preparation of public health communication was recently demonstrated in the UK where researchers were able to obtain a video that the Department of Health had intended would be used only in a catastrophic influenza pandemic. Whilst, the details of FOI legislation might vary from state-to-state, the general principal behind such frameworks is that members of the public have a right to request many types of diverse information. Such information could include material that might appear to undermine the choice of message that has been disseminated to the public. Given that an 'unintended unearthing' of such material could have negative consequences in terms of trust in a public health campaign, the effect of FOI legislation is to encourage a maximum level of transparency, even where this means releasing information that may be perceived as unhelpful.



Ethical and Political Issues Surrounding the Use of Private Stakeholders

Despite the lack of legal compulsion upon public health programs in general, the central aspects of the NFM mean that it allows some of the issues described above, that are associated with good governance, to be incorporated into public health campaigns. Even though such practices may not be legally required, their inclusion may be desirable from both an ethical and practical sense. In particular, the emphasis on an interactive approach with stakeholders of various types in society is important. Communication with such stakeholders through accessible and interactive means (including *inter alia* social networks and online platforms) will allow individuals and groups in society to express concerns regarding the potential emphasis in public health messages and any potential negative effects that this might have. The emphasis in the NFM on a strong pre-pandemic phase of preparation and co-ordination with stakeholders will, in particular, provide a chance for affected parties to highlight and discuss the use of potential information that may be harmful (e.g. where it is stigmatizing or conducive to discrimination) long before a pandemic arises. Such processes are important because they might allow some of the harmful effects associated with public health campaigns to be avoided beforehand. In addition, an emphasis in the NFM on post-pandemic planning and analysis will allow important lessons to be learned in terms of harmful effects, lessons that can be of use for subsequent public health crises.

Whilst the integral use of a wide range of stakeholders will allow a much greater interaction with the public, it brings with it added complications that entail a far greater reliance on private parties than traditional models of public health communication. This can raise both ethical and political issues because private organizations are not subject to the same accountability mechanisms (i.e. control through executive and legislatures) that public bodies will often be. The result is that individuals are not able to influence stakeholders and other private parties through the ballot box as would be the case if they disapproved of an action by public organization. This lack of accountability can worsen problematic issues that may be associated with the use of private bodies in public health projects. This can include for example a potential non alignment of interests where stakeholders are included that have different aims than the public health campaign in general. A further issue concerns a lack of fair representation of various elements in society, with a disproportionate amount of attention going to stakeholders with a primarily commercial interest. One possible solution that has been suggested for such accountability problems is to arrange relationships with stakeholders (where possible) through well-defined Memoranda of Understanding (MoUs). In such MoUs it would be possible to clearly define roles, interests and expectations and hopefully minimize such problems.

Further political problems can be raised through the selection of particular stakeholders and community representatives. The selection of such stakeholders is sensitive because such parties will become at least to a certain extent associated with the state, despite being private in nature. This can cause problems where a particular stakeholder is associated with ideas or beliefs that may be offensive to other groups in society. This might for example exist where stakeholders represent the views of religious communities that may be hostile to the lifestyle choices or beliefs of other groups in society. There exists the danger that the involvement of such parties could mean that the state inadvertently becomes associated with such views. This would be incompatible with the image of neutrality *vis-a-vis* the many and varying groups that the state or public bodies are expected to in a pluralistic democracy. Such a position of neutrality is important in maintaining the 'self-respect' of minorities and vulnerable groups, something that is important in their ability to withstand stigmatizing forces. It will thus be important to consider the

background of potential stakeholders and screen for problems of this nature. Given the diverse and plural nature of societies it will be difficult if not impossible to find any group that is not offended, or does not cause offence to other groups in society. Whilst it may be impossible to design an effective communication campaign and find only stakeholders that have completely unblemished reputation of tolerance to all groups in society, efforts should be made to avoid extremist or overtly intolerant elements. This problem can once again be further reduced through the use of MoUs that underline that public health bodies cannot be associated with divisive, sectarian or intolerant attitudes and represent all groups equally.

A similarly sensitive issue will involve the selection of stakeholders or groups pertaining to minority languages. In some societies the utilization of minority languages may be politically sensitive and symbolic of perceived failed efforts to integrate with host societies or may be used by extreme elements to argue that the majority culture is threatened. In other societies where there exists a history of plurality in terms of language and culture, the use of language may be connected to sensitive political questions of sovereignty. In such societies the use of a particular language may be mandated in public communications or others forbidden. This can pose problems for public health organizations that may want to reach minorities in other languages. In such situations the use of a particular community stakeholder, as envisaged in the NFM, might provide an opportunity for expression in languages that might not be possible for public bodies. This is because such stakeholders will often not be bound by the same legal restrictions and political sensitivities of the state and, as a consequence, will be able to use a non-official language more freely.

## Introduction

The emphasis of the first part of this deliverable is upon the potential impact of legal frameworks on the Operation of the TELL ME New Framework Model. In doing so, this document will consider the applicability of binding legal frameworks and their potential implications for the NFM. This document does not purport to present an exhaustive analysis of all potential laws that could have an impact upon the NFM (given the number of potential jurisdictions involved such an endeavour would be far beyond the scope of this deliverable). The aim of this deliverable is rather to highlight key legal issues that may relate to the use of the NFM. The emphasis will then move to the potential non-applicability of national systems of administrative law and the relevance of this for the NFM given that such systems play a primary role in protecting the interests of individuals from actions by the state. The report will then consider how data protection laws (in Europe) and freedom of information laws will be capable of having in the NFM.

The second part of this document will move on to potential ethical and political implications of the implementation of the NFM. This will include at the look at potential requirements associated with the practice of good governance that should be considered by public bodies involved in the NFM. These requirements are particularly important in the context of the NFM because, unlike with most other types of acts by public bodies, such practices are not compelled by law for purely informational acts such as public health information campaigns. In addition the problems associated with the use of private stakeholders in the NFM will be discussed.<sup>2</sup> The final sections of the document will consider the political implications that could follow from the choice of certain stakeholder that could be considered sensitive or offensive to other groups in society.

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<sup>2</sup> For an analysis of the types of stakeholders that could be used under the NFM see TELL ME Deliverable 2.1 – Stakeholder Directory and Map

## Part 1 – Legal Issues Surrounding the New Framework Model

### 1. International legal Obligations on States

#### 1.1. The IHR and the World Health Organisation

The International Health Regulations (IHR), created under the auspices of the World Health Organisation, are amongst the most important legal obligations on states in the context of public health. Unlike most other initiatives of the WHO that take the form of non-binding agreements (so called ‘soft law’) the IHR is binding upon signatories (Coker et al. 2008).<sup>3</sup> The regulations created a system of global surveillance for the emergence of infectious disease (Baker and Fidler 2006). The new regulations are much broader than the prior incarnation (i.e. the IHR 1969) which was only concerned with the ‘quarantinable’ conditions of cholera, the plague and yellow fever. In addition, the IHR 2005 has a much more expanded breadth of application, resulting in an increase in WHO authority in the co-ordination of public health threats between signatory states. It envisages a much more onerous system of surveillance and requires particular responses if certain conditions are met.

The four key tenets of the IHR have been accordingly described as (Webber et al. 2010)

- Risk assessment,
- Identifying a Public Health Emergency of International Concern (PHEIC),
- The creation of a 24/7 communication network through National Focal Points (NFPs)
- Establishing core public health capacities at the international level.

The IHR does not explicitly outline any obligations on states or other parties in terms of requirements for communication to the public and other stakeholders during an epidemic. In general, its tone and content is preoccupied with the collection of data and the relaying of important information to the relevant authorities at the national and international level. It does however describe obligations that could be understood as relating to responsibilities of public health education. These include obligations to develop core public health capacities with Articles 5 and 13 stating for example requiring “the capacity to respond promptly and effectively to public health risks and public health emergencies of international concern”. Such requirements are understood by the WHO to implicitly include requirements in terms of public communication given “that risk communication is the dissemination of information to the public about health risks and events, such as outbreaks of disease.” In addition meeting such core competences requires an appreciation that<sup>4</sup>:

*“Risk communications should be a multi-level and multi-faceted process which aims to help stakeholders define risks, identify hazards, assess vulnerabilities and promote community resilience, thereby promoting the capacity to cope with an unfolding public health emergency ... For any communication about risk caused by a specific event to be effective, it needs to take into account the social, religious, cultural, political and*

<sup>3</sup> Another notable exception is the Framework Convention on Tobacco Control

<sup>4</sup> IHR Core Capacity Monitoring Framework - Checklist and Indicators for Monitoring Progress in the Development of IHR Core Capacities in States Parties April 2013 WHO/HSE/GCR/2013.2

*economic aspects associated with the event, as well as the voice of the affected population.... Communication partners and stakeholders in the country need to be identified, and functional coordination and communication mechanisms established. In addition, it is important to establish communication policies and procedures on the timely release of information, with transparency in decision making, that is essential for building trust between authorities, populations and partners.”*

Whilst the IHR itself does not say very much about the requirements of effective communication strategies during epidemics, the comments by the WHO here suggest that it see the establishment of multi-faceted approach that is inclusive of elements representing the many and diverse groups of stakeholders in society as an integral part of the core capacities required by states by the IHR. Such requirements should accordingly be viewed as forming part of the requirements of the IHR upon states.

An analysis of the aims and priorities of the NFM shows that it attempts to meet many of these challenges directly. In particular the focus the NFM gives to the involvement of stakeholders in pandemic communication strikes an accord with the tone used by the WHO in its analysis of the core requirements of IHR. This openness to stakeholders and various societal groups in the NFM, as a tool of effective communication, will allow a pandemic response to take into account the “*social, religious, cultural, political and economic aspects associated with the event*” as described by the WHO. In addition the involvement of such stakeholders in the manner described in the NFM should aid in allowing an interaction of the part of the various groups in society that would allow for a high level of trust in the public health response in times of a pandemic. In particular the NFM would appear more compliant with such aims that more traditional models top-down methods of public health communication that place less emphasis on interactivity and the role of such a diverse set of stakeholders. Given these factors the adoption of the NFM by international and national public health bodies can be consistent with the obligations that exist in the IHR.

## 1.2 European Union Law

The European Union has been provided with very little competence in the areas of health policy. Its competence relates to the co-ordination of activities in areas where such co-ordination would be beneficial and the Member States of the European Union have consented to such co-ordination. This state of affairs is clearly delineated in Article 168 of the Treaty on the Functioning of the European Union.<sup>5</sup> It states *inter alia* that the Union’s role is limited to ‘complementing national policies’. In doing this, the Union is able to ‘encourage’<sup>6</sup> cooperation between Member States in certain areas of public health.<sup>7</sup> An example of this involves a recent initiative by the European Union on the joint procurement of vaccines.<sup>8</sup> In order to encourage such cooperation, the European Parliament and the Council, acting in accordance with the normal legislative procedure, are able to release guidelines recommending measures that Member States

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<sup>5</sup> Together with the ‘Treaty on the European Union’ these treaties, signed by the Member States of the EU have in effect constitutional significance for the EU.

<sup>6</sup> TFEU, Article 168(2).

<sup>7</sup> TFEU, Article 168(1) – ‘Union action, which shall complement national policies, shall be directed towards improving public health, preventing physical and mental illness and diseases, and obviating sources of danger to physical and mental health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education, and monitoring, early warning of and combating serious cross-border threats to health.’

<sup>8</sup> *European Commission Press Release*, April 10, 2011 [http://europa.eu/rapid/press-release\\_IP-14-418\\_en.htm](http://europa.eu/rapid/press-release_IP-14-418_en.htm)

should take in order to achieve such cooperation.<sup>9</sup> An example of European cooperation that is very relevant to pandemic preparedness has been the establishment of the European Centre for Disease Control (the ECDC). Whilst this body has *inter alia* released revised guidelines communication for influenza epidemics (including a tool kit that can be used by authorities in the member states)<sup>10</sup> such guidelines do not have binding force on European states and as a consequence create no legal obligations. Whilst such guidelines may be useful to Member States they can simply ignore them if they so wish. As a consequence such guideline will not be considered here in the context of potential legal obligations. The legal situation within the European Union means that in practice the centre of gravity of legal power in the area of public health rests very firmly with the Member States (Brooks, 2012). As a consequence the EU has not enacted any binding regulations or directives concerning the communication programmes that a Member State must follow in a health crisis. There exists thus little in the way of EU law to consider in terms of the potential legality of the TELL ME New Framework Model.

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<sup>9</sup> TFEU, Article 168(4).

<sup>10</sup> A copy of the tool kit can be found at [http://www.ecdc.europa.eu/en/healthtopics/seasonal\\_influenza/communication\\_toolkit/Documents/ECDC\\_Influenza\\_toolkit\\_guidelines.pdf](http://www.ecdc.europa.eu/en/healthtopics/seasonal_influenza/communication_toolkit/Documents/ECDC_Influenza_toolkit_guidelines.pdf)

## 2. Human Rights Law

Legal instruments that speak of, or create human rights can be found at the international, regional and national levels. The IHR (described above) recognises that states should respect human rights and the concept of human dignity in their implementation of that agreement. Prominent examples of international instruments include the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic and Social Rights. At the regional level the most known and far reaching is the European Convention of Human Rights (the ECHR) which has been created by the members of the council of Europe and (for which all members of the EU are for example signatories). Another important source of human rights law in Europe is the Charter of Fundamental Rights of the European Union (The EU Charter), which since the Lisbon treaty has had binding effect.<sup>11</sup> This charter is binding upon on EU institutions and not directly on Member States. It will therefore have a minimal direct effect on laws and rules relating to the provision of healthcare, as the EU itself has almost no competence in this area.

### 2.1 Human Rights that are Applicable in Epidemic Situations May be of Little Direct Applicability to the New Framework Model

These instruments which have been signed by a number of states, to a varying degree create legally enforceable rights within those states (especially the ECHR), and provide a number of rights that might be applicable in pandemic situations similar to that for which the TELL ME New Framework model is attended to apply. These were described in TELL ME Deliverable 1.6.<sup>12</sup> Notable examples include:

- **A Right to Health** (an economic and social right that is not generally enforceable) e.g. Article 25 of the Universal Declaration of Human Rights, Article 35 of the European Charter
- **A Right to Life** (a right generally understood as being negative in nature and ensuring that individuals cannot be subject to measures that would risk their lives, except in limited circumstances) e.g. Article 2 ECHR
- **Freedom from Torture and Inhuman or Degrading Treatment** (This right may be applicable in some cases of compulsory treatment) e.g. Article 3 ECHR
- **The Right to Liberty and Security of Person** (Also sometimes used as a right against compulsory treatment e.g. Article 5 ECHR
- **The Right to Private and Family Life** (Can create a range of rights including the right to treatment in certain contexts, rights of privacy e.g., confidentiality) e.g. Article 8 ECHR

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<sup>11</sup> Charter of Fundamental Rights of the European Union (2000/C 364/01)

<sup>12</sup> See Tell Me Deliverable 1.6 Report on stigmatization and risk of discrimination and human rights.

- **Rights of non-discrimination** (People should not be treated differently unless there is a reasonable and objective reason for doing so) e.g. Article 8 ECHR

These rights will have, to varying degrees, an impact upon the public health authorities and how they can behave in a crisis. In most instances however such rights will be applicable in situations where the actions of such authorities directly impact on individuals in a physical manner. This may for example include the imposition of quarantine, ordering compulsory treatments or vaccinations, ordering the closure of schools or work places.<sup>13</sup> The potential applicability of human rights to such situations was discussed in Deliverable T1.6 and will not be replicated here. This is because this deliverable pertains to the legal implications of the New Framework Model of communication developed for the TELL ME Project. This model does not relate to such interventions on individuals but rather relates to a framework for communication during pandemics. Whilst such activities can of course have effects on individuals (e.g. allowing individuals to be better informed about a healthcare threat), it is doubtful whether such purely informational activities are capable of engaging human rights principals that are normally associated with the provision of healthcare (with the exception of those described below). This is because such actions have little effect on the material situation of individuals, nor do they compel individuals to do something (or desist from doing something) (Quinn and De Hert 2014). In contrast to orders relating to the closing of schools or airports or orders mandating compulsory testing or vaccination for example, individuals are simply free to ignore any and all information and advice they are provided with by public health communication networks. Rights pertaining to such physical concepts as a 'right to life' or a right to physical integrity are therefore of little application to such a framework model for communication.<sup>14</sup> The situation may however be different for rights that have been associated with psychological effects that can be produced in individuals. Given that public health communication can produce effects such as stigmatisation and can sometimes be responsible for the creation of a discriminatory atmosphere, the potential application of these rights is interesting in the context of this deliverable.<sup>15</sup> The rights concerned are discussed below.

## 2.2 Human Rights Potentially Applicable to the New Framework Model

The situation concerning other rights that are more likely to apply to communication activities is less clear. This includes for example rights not be treated in an inhuman and degrading manner, rights to private and family life and a right of non-discrimination. Such rights could seemingly be more applicable to public health communications. One could envisage that individuals who were affected by insulting, humiliating, discriminatory or stigmatising remarks might for example seek to argue that their human rights had been affected. As deliverable 1.6 discussed some public health campaigns stigmatize unintentionally, whilst others, e.g. anti-smoking or anti-obesity campaigns, use stigmatization as their primary weapon (Bayer, 2008). The application of these rights to the purely informational types of act that public health communication envisaged in the New Framework Model is however contentious, even where messages may contain negative content relating to individuals or groups (Quinn and De Her 2014). These issues are discussed below.

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<sup>13</sup> See for example the *Herczegfalvy v Austria* (Series A, Volume 242-B; Application No 10533/83) European Court of Human Rights (1993) 15 EHRR 437, 24 SEPTEMBER 1992. This case concerned the force feeding someone who was allegedly mentally ill.

<sup>14</sup> It is of course possible that the New Framework Model could be used to disseminate advice to states to act in a manner that would engage such rights. Considering all possible strategies that the New Framework model could be used to advocate would however be beyond the scope of this task and shall accordingly not be considered.

<sup>15</sup> The induction of these effects is discussed at greater depth in TELL ME Deliverable 1.6



### Freedom from Inhuman or Degrading Treatment

This right is described *inter alia* in Article 3 of the ECHR. It is an absolute right and demands that individuals are treated with dignity. It has been discussed and applied in cases related to healthcare, particularly in the context of forced treatment e.g. *Jalloh*.<sup>16</sup> Whether simple pronouncements or the provision of healthcare information (such as that envisaged in the NFM) could be capable of engaging Article 3 e.g. when they were discriminating or insulting, is however less certain. The European Court of Human Rights (the ECtHR) in the case of *Oršuš*<sup>17</sup> has invoked the possibility that the right of freedom from inhuman and degrading treatment (in Article 3 ECHR) could be engaged where a victim is humiliated “in his or her own eyes”. This would be an extremely high bar for the information provided by a public health system to reach. It is difficult to envisage how this would occur in practice barring the use of insults or condemnations that were leveled at particular groups, something which is difficult to envisage and which would not be acceptable practice in the field of public health. This is because whilst (as deliverable 1.6 showed) it is possible to cause stigmatization or offence for groups accidentally during public health communication, it is difficult to imagine public health communication that would ‘humiliate’ individuals.<sup>18</sup> Setting such a high bar for the engagement of this right is understandable. This is because unlike other prominent human rights (e.g. the right to a private and family life) the right of freedom from inhuman and degrading treatment (described in Article 3 ECHR) is not qualified. This means that the engagement of the right cannot be justified in any circumstances. The practical result of this situation is that any engagement is *prima facie* illegal and that there is very little room for a court to take into account the circumstances of the situation in order to discern whether such engagement is justified (this process is described in more depth below). As a consequence, setting a low bar for the engagement of such a right would likely make many types of essential activities illegal. This could potentially include the dissemination of some forms of information or advice that might be considered stigmatizing for some groups in the context of a public health campaign. Given that in large populations it is likely that one group or another may find public health information offensive, a lower bar might preclude the release of information that is essential but which could be capable of causing offence or of being perceived of insulting by certain groups in society.

### The Right to private and Family Life

Similarly, the ECtHR has recognized the right of individuals to form relationships falls under the right to a private and family life (Article 8 ECHR). It is therefore conceivable that public health messages that were able to damage the ability of individuals to form relationships might be capable of engaging such a right (Quinn and De Hert 2014). This might for example occur where public health campaigns use material, make statements or provide information that was capable of stigmatizing individuals. Deliverable 1.6 demonstrated numerous examples of how this can occur in the context of public health campaigns, as a result of communications designed to provide information concerning a threat to public health.<sup>19</sup> This could occur, for example, where public health figures wrongly attribute the behavior of certain minorities as a factor in a disease spreading, or create suspicion and concern surrounding a group that has perceived

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<sup>16</sup> *Jalloh v. Germany* (n°54810/00) E.C.H.R. (Grand Chamber), 11.07.2006

<sup>17</sup> *Oršuš and Others v. Croatia* (application no. 15766/03)

<sup>18</sup> See also *A, B and C v Ireland* [2010] ECHR 2032 for a description of the high threshold required in order to show such humiliation.

<sup>19</sup> See also Guttman & Salmon, 'Guilt, Fear, Stigma and Knowledge Gaps', (2004), *Ethical Issues in Public Health Communication*, 18, 531-552

connections to the geographic location where outbreak of the disease in question commenced. Where such stigmatization occurs, it can cause social harm to the individuals involved, harming their ability to form relationships in society (Dovido 2000). Stigmatization has for example occurred in numerous countries concerning individuals who had ties to Mexico in the H1N1 outbreak in 2009 (Gallagher, 2009) and also for members of East Asian communities (in particular the Chinese community) during the SARS outbreak in 2003 (See for example (Perry & Donini-Lenhoff, 2010, Schram, 2003 & Eichelberger, 2007)). Given the potential negative effects of stigmatization on such affected communities, the court has shown itself to be open to the issues that stigmatization can cause, including problems associated with treatment avoidance. This was demonstrated in the *Kiyutin* where the ECtHR notably pointed<sup>20</sup> to a declaration by the UN General Assembly, which recognized that the issue of stigma for those who are HIV positive can have negative effects on efforts designed to prevent the spread of the virus and treat those infected with it.<sup>21</sup> In addition, the court highlighted that the General Assembly's assertion that the "full realization" of human rights principles would reduce stigma, allowing benefits in terms of prevention and treatment.

The sensitivity that the court has shown to potential issues of stigmatisation however does not necessarily mean that it would be willing to rule a stigmatising statement made by public health authorities, by itself, to be contrary to an individual's right to a private or family life. In most of the cases where the court has considered stigmatisation as a factor in the potential violation of an individual's rights under Article 8 ECHR, it has been in the context of another engaging factor. This has included for example, the retention of genetic samples or the deportation of individuals found to be positive for HIV. In each of these cases the court has considered stigmatisation in the context of these much greater effects on individuals (Quinn & De Hert 2014). Such a consideration relates to a legal conceptualisation the court uses to decide whether a violation of Article 8 ECHR has actually occurred. This involves a two stage process. The first involves determining whether there has been engagement of a right in question whilst the second involves determining whether such an engagement has been justified. In deciding the second factor the court can *inter alia* take into account whether such engagement was proportional and necessary in a democratic society. It is at this second stage where the court has decided to factor in the stigmatising nature of a measure in order to decide if such engagement was proportional. It has thus far however never considered stigmatisation alone to be an engaging factor. This is important because without having first established an engaging factor a court will not go further to assess whether such an engagement was justified or not, and therefore whether a breach has occurred. Given that the court has not yet considered that stigmatisation alone, without any other engaging factor is sufficient to constitute the engagement of a right it is doubtful whether a court would consider stigmatising statements, advice or releases of information in the context of a public health campaign to constitute an engagement of Article 8 ECHR. This may mean individuals may not be able to find protection under Article 8 ECHR, in cases where they have been stigmatised by pronouncements in public health campaigns, including in the context of the New Framework Model produced in the TELL ME project. The authors' of this paper would however like to point out that one possible reason for this may simply be because no case of this type has come before the ECtHR as of yet. If this were to happen the ECtHR might of course react differently to such 'stigmatisation alone' than it has hitherto done so (Quinn & De Hert 2014). There are, however, further problems for individuals wishing to bring such cases to court given the difficulties that such individuals may have in gaining traction through their respective administrative law systems. These problems can compound the issues of 'non justiciability' that surround information's campaigns by the state. (These problems are discussed further in

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<sup>20</sup> *Kiyutin v. Russia* (Application no 2700/10) para 27

<sup>21</sup> United Nations General Assembly Declaration of Commitment on HIV/AIDS (Resolution S-26-2).

section 3 of this document concerning the apparent lack of applicability of administrative law to public information campaigns).

### A Right of Non Discrimination

Deliverable 1.6 discussed both the existence of various rights against discrimination and also how a discriminatory environment can be promoted in the context of a medical health emergency, including in during pandemics. However, this deliverable is not concerned with the general conditions present in an epidemic type situation, but *inter alia* the potential legal constraints on public health communication programmes of the type described in the TELL ME New Framework Model. This discussion of rights of discrimination in this deliverable will be therefore be limited to potential effects vis-à-vis the New Framework Model. This model is primarily concerned with communication activities. It is therefore necessary to ask what impact a right of non-discrimination can have upon activities that are solely of an informational nature. This distinction is important because communicational activities such as those envisaged in the NFM are concerned with the provision of information to individuals and do not generally involve impositions or changes in the legal rights of individuals. It is such effects that courts usually consider in non-discrimination cases. Given this, the application rights of non-discrimination by individuals who feel they have been harmed by the statements or information produced in public health campaigns such as the NFM is doubtful.

The fight against discrimination in general involves a struggle for a form of equality. When equality is invoked in legal terms (in particular in requirements of non-discrimination) the meaning is obviously not material or economic but refers to the concept of equality before for the law. The Fourteenth Amendment of the US Constitution, for example, (which is often invoked in American cases of discrimination) requires that states not act to “deny to any person within its jurisdiction the equal protection of the laws ”. Discrimination as a concept in terms of equality before the law requires that individuals are not denied their legal rights or treated differently by the laws of the state because of certain characteristics. Initially, in discussing what discrimination is, the ECtHR used a more formal “Aristotelian” concept of equality that asks whether there had been a difference in treatment between individuals in the same circumstances.<sup>22</sup> Starting from this “de jure” notion of equality the court has, in recent years, shown an increasing sensitivity towards a “de facto” notion of equality (O’Connell, 2009). Such efforts look more at the effects of the measure in reality and less at the superficial equal treatment of individuals in the same manner. In such an approach the focus is therefore more on differential outcomes than upon equal treatment. Under such an approach the state need not act any differently in its treatment of individuals or intend to treat them differently, but can be considered as having acting discriminatorily if, because of their differing situations the outcome would be (unjustifiably) different. Imagine for instance a law that stated that ‘all individual are entitled to vaccination free at their local GP’. Such a law might not be considered discriminatory under a *de jure* notion, but might well be considered *de facto* discriminatory given that some people in society may not have a GP or may not be able to register with one (imagine for example groups such as illegal immigrants etc.).

The existence of the notion of ‘de facto’ forms of discrimination raises the question of whether a court would consider effects of informational acts, that do not *prima facie* involve treating individuals differently, as being discriminatory. This might occur, for example, when communications by the state

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<sup>22</sup> For an excellent analysis of the ECtHR’s approach to discrimination, see O’Connell (2009)

cause certain groups to feel stigmatized or more at risk of discrimination. This question is relevant if one envisages information campaigns that may, in a *de jure* manner treat individuals the same (by providing them with the same information), but for which the effect of such information could be different. For example, this may occur when, as a result of statements or information provided, certain groups become stigmatized e.g. foreigners, those already sick etc. (see deliverable 1.6 for more examples of this) or had been placed in a discriminatory environment (where others might, as a result of the information provided, be induced to act discriminatorily. If a court was willing to see such actions as discrimination, this would mean that it might be possible for individuals to claim that they had been discriminated against by public health campaigns that led to them being stigmatized or increased the chances that they were stigmatized against.

Despite this openness to a ‘de facto’ analysis of what constitutes discrimination, the ECtHR and many other important courts have however shown themselves unwilling to find that simple statements or provision of information is likely constitute discrimination. This is because at the heart of the ECtHR’s (and that of other human rights instruments) anti-discrimination approach remains the notion of equality before the law. Discrimination requires changing the legal rights of one individual relative to another because of a characteristic that should not be taken into account. Indeed the ECtHR is restricted by the wording of Article 14 ECHR which states “The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination.”. This wording focuses the concept of discrimination clearly upon the effects that measures have on the other legal rights established in the convention. An even better example is provided by the International Covenant on Civil and Political Rights that describes discrimination by stating, “All persons are equal before the law and are entitled without any discrimination to the equal protection of the law.”<sup>23</sup>

However, with public statements or the provision of information (i.e. the activities envisaged in the NFM), the government body concerned does not change the legal rights of individuals but merely expresses itself on a certain matter. Such expression does not compel individuals to act in one manner or desist from acting in another by virtue of them possessing a certain characteristic. Individuals are free to ignore the expressions of the state in such instances and carry out their conduct as they wish.<sup>24</sup> Those who are the subject of discrimination are however bound by the discriminatory formulation of their legal rights. The ECtHR demonstrated its agreement with such thinking in the case of *Baczowski*.<sup>25</sup> In that case a Polish mayor made homophobic comments about the homosexual community in Warsaw who wanted to organize a gay pride march. In that case the court illustratively stated that such statements alone (without action) could not be thought of as constituting discrimination under Article 14 ECHR. As a consequence, it is unlikely that individuals will be able to challenge the provision of public health related information using human rights provisions against discrimination e.g. using Article 14 ECHR.

## Section 2 – Summary Points

- **Whilst a selection of human rights might be applicable to epidemic situations in general (see deliverable d1.6), most will not be directly relevant to information campaigns.**
- **Rights that may be of potential applicability include the right not to be treated in an inhuman or degrading manner, the right to a private and family life and a right not to be discriminated**

<sup>23</sup> International Covenant on Civil and Political Rights Article 26.

<sup>24</sup> This issue of lack of legal effect and its consequent implications in terms of the non engagement of various systems of law is a theme that is repeated throughout this document and which is capable of creating issues of ‘non-engagement’ various systems of law. See for example the example of administrative law.

<sup>25</sup> *Baczowski & Others v Poland* [2007] ECHR No.1543/06

against.

- The applicability of these rights is however by no means certain. The European Court of Rights has for example set an extremely high threshold for the invocation of inhuman or degrading treatment and has, thus far, never found stigmatizing statements by the state (*inter alia* in activities such as public health campaigns) without some other engaging factor to be a violation of the right to a private and family life
- Additionally, the court has indicated that statements or expressions alone are unlikely to be viewed as discriminatory acts unless accompanied by some activity that affects individuals legal rights.

### 3. The Importance of Administrative Law in Protecting Individuals from the Actions of Public Bodies

Administrational law in most western states represents an important mechanism for allowing control of the state and its personnel (Rose-Ackerman & Lindseth 2011). It allows individuals to have administrative decisions assessed for a number of factors in an official tribunal, often a court. The availability of administrative law therefore represents an important instrument in allowing individuals citizens to hold the state and public agencies to account (Harlow 2006). This is important because the state and related public agencies have a level of power over citizens that has no other equivalent amongst other private actors (either legal or natural). In comparison with private citizens the state has at its disposal the ability to choose to distribute economic resources, to levy taxation, to create legal permissions or even to take actions that affect civil rights such as voting and political activity. In addition the state, given its organization and financial resources, has enormous power in terms of the gathering, processing and dissemination of information (and Margretts 2006). Such powers go far beyond that which is available to private individuals who are (at least in theory) limited to consensual legal agreements in the form of contracts or are required to compensate other individuals where their actions cause harm e.g. in tort law. Whilst a citizen can in general avoid such legal relationships through not contracting with or causing harms to other individuals, they are unable to avoid such contacts with the state. The modern state has evolved to be involved in such a vast array of areas that it is almost impossible to avoid contact with it one or the other in day-to-day existence. Amongst such forms of interactions, there are those that come about as a result of the state's activities in the area of public health including where it is responsible for the creation of public health campaigns, including activities of the type envisaged in the NFM. The range and depth of potential for abuse by civil servants and public bodies of such powers is vast. As a consequence the availability of administrative laws that restrain such individuals and allow them to be challenged by private citizens in independent tribunals is essential. Where such an ability does not exist there exists the risk that civil servants and public bodies could act with impunity, causing harm to groups and individuals in society. Given that (as deliverable T1.6 showed) it is possible for public health campaigns to create harmful effects for some individuals and groups in society it is necessary to ask what protection individuals might be able to find in administrative law from such activities (including as in envisaged in the NFM). This issue is addressed below.

#### 3.1 Limited Control Over Informational Activities Through Administrative Laws

The ability of administrative law to regulate the flow of information or the giving of statements, e.g. in the context of a health information campaign, is limited. This is because the engagement of administrative law with an administrative act is usually dependent upon the creation, removal or alteration of legal rights of individuals by the act in question (see for example (Craig, 2012: 339)). If such an act is not accompanied by an alteration in an individual's legal status then this means that in many jurisdictions the informational act will not be classed as an administrative act and therefore will not be reviewable by an administrative tribunal.<sup>26</sup> This potential lack of administrative law applicability is important for the NFM given that it, like most types of public health information campaigns, essentially involve the dissemination of information by

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<sup>26</sup> Such a general situation also exists in US Federal Administrative Law by virtue of the Administrative Procedure Act 5 U.S.C §§ 551-599

the state to various groups in society but do not involve actions that create, remove or alter the legal rights of individuals. Such legal effects can occur in public health activities, for example where a public organisation decides on the availability of medicines, testing or treatment to certain groups of the population, or where on occasion they may undertake certain forms of compulsory treatment or preventative methods such as restrictions on travel (see deliverable 1.6). With public health campaigns (including of the type envisaged in the NFM) that are purely information nature, there are usually no legally binding effects on individuals. As a consequence, such acts (i.e. public health campaigns) will not be a reviewable as an administrative act under most systems of administrative law. This means *inter alia* that public authorities have a relatively free hand to design, organise and implement such public health campaigns as they see fit (Quinn and De Hert 2014). In addition, public health authorities often do not need to worry about adhering to the normal requirements of an administrative act. This means that a number of checks and balances that would normally apply to an administrative act would not apply to an informational act such as a public health campaign. These include checks on legality, form and adherence to important legal principals. The importance of these and the relevance of their non-applicability to public health information campaigns such as the NFM are described below.

#### Lack of Legality

Perhaps the most important grounds for challenging an administrative law decision is its lack of legality. Such grounds relate to the fact that ministers, civil servants and others that represent the state should have a legal basis for their actions. Such authority can exist in statutes created by parliament and various forms of secondary legislation. Such judicial checks form the oldest and most established grounds for judicial review, especially in common law countries (Harlow 2006). In the US, such grounds for review are associated with the longstanding and fundamental principal of limiting the role of government (Harlow 2006). In the UK, for instance, the doctrine of *ultra vires* has long been established. This doctrine allows courts to rule decisions or acts illegal if the minister or civil servant involved cannot refer to primary or secondary legislation that does not permit such decisions. In French a similar ground for review exists and is known as *excès de pouvoir*. Such a basis for judicial review is important in allowing individuals to prevent ministers, public bodies and civil servants from taking actions for which they have no authority and which are capable of producing harmful effects for individuals concerned. Given that the NFM (involving primarily informational acts) will not usually be subject to administrative review, public bodies will not be subjected to a check for legality when carry out the activities that are envisaged within it.

The effect of not having to strictly adhere to a principal of legal means that public organizations have a great degree of flexibility in deciding how to organize public health campaigns. They need not usually refer to explicit authorization in statutes or other types of legislation granting permission to operate such a campaign. This means that campaigns can be established quickly and according to the format which the public authority in question finds most suitable. As a consequence public health authorities will likely be able to adapt all of the aspects of the NFM that relate to them. They are able to plan, organize and carry out such campaigns as they see fit. In addition public holders will be able to engage a variety of stakeholders to partake in communicative activity as is envisaged in the NFM. As a result they are free to dispense information and advise as they choose and involve other parties such as private and community organizations as they see fit. This flexibility is important in the context of preparing for and reacting to a potential influenza pandemic as it will allow potential stakeholders from a wide range of back grounds quickly without being restricted by the exact specifications of existing legislation.



*A Lack of Checks on Adherence to Normal Standards of Form*

Administrative law also often requires that decisions are made in a certain manner, or in an appropriate form. Such grounds do not seek to specify exactly what course of action an administrator should choose, but pertain more to how the decision is made. At the heart of such grounds is the need to ensure that principles of good governance are observed. As one commentator states, good government in the administrative context involves ideals of “openness, fairness, participation, accountability consistency [and] rationality” (Aronson, 2004:193). Given that the potential non-applicability of administrative review in purely informational activities (such as the NFM) raises concerns about a lack of compulsion to implement practices associated with good governance.

Perhaps the most important requirements in terms of form are a duty to consult individuals that may be affected by administrative decisions, a duty to give reasons for decisions (often demonstrating the varying factors that have been considered in reaching a decision), and a duty to review periodically decisions that have already been made. The existence of such aspects in administrative matters helps improve the overall experience of governance in several ways. Most notably, it compels administrators to consider relevant criteria, to listen to the opinions of others who might be affected and who may possess useful information unbeknown to the administrator and to review matters for changes in circumstances. A duty upon administrators to provide reasons is particularly important in allowing individuals to understand both the motivations behind a decision and the factors considered in making such a decision. The availability of such reasons allows individuals to know whether the administrator in question acted properly in terms of other requirements including those of legality and issues of form. The need to implement such requirements therefore can be thought of as a need by administrators e.g. civil servants and ministers to incorporate recognized elements of ‘good practice’ in their decision making. Such good practice allows decision makers to be as well informed as possible, being aware (as much as is possible), of both the negative and positive effects of their actions. They additionally allow individuals the ability to understand why such actions were taken so that they can see for themselves that the decision maker was acting in a legal manner.

The non-applicability of administrative law to purely informational acts means that the normal rules of form that apply to administrative acts would not apply to most types of information-based public health campaigns, including most of the activities envisaged in the NFM. In short, this means that the normal obligations of prior announcement, consultation, consideration of public representation and subsequent review of decisions will not apply. This can be seen as bringing with it both advantages and disadvantages. In terms of advantages, the most notable is once again a high level of flexibility, especially in comparison with other areas of state activity which are more restricted by formality requirements. Public health campaigns that are solely informational in nature will not therefore need to wait until after a prior announcement has formally been conducted or wait for the results of any public consultation. On the contrary, public authorities, for the most part, are simply able to commence information campaigns immediately in a manner in which they would wish. This provides an important level of flexibility for public health planners that may need to react quickly to emergency situations. Such individuals may be faced with a fast-emerging situation that may require a response that changes from hour to hour. Having to take the time to comply with the normal formality requirements of government acts could make the necessary responses impracticable and would make it impossible for public health officials to keep pace with changing events. In addition, public health officials will be free in terms of the form they adopt, not having to restrain themselves to requirements that have already been laid down. This presents important possibilities in



terms of using new formats and fora to distribute messages. Public health officials will generally be able to distribute any message how they see fit, using whatever format is deemed to work best. This flexibility will be important in allowing the New Framework Model the flexibility it demands to forge contacts with the wide variety of stakeholders that may exist in an epidemic situations. Such stakeholders may change from one context to the next, as may the means that needed to communicate with them and through them.

Viewed from another perspective, such flexibility and freedom from restriction in terms of form also has disadvantages. Requirements of form are not meaningless burdens on administrative acts but representative requirements that, with the experience of time, have become to be seen as synonymous with the practice of good governance. Requirements of consultation and the need to give reasons mean that public servants often need to consider the views of individuals that may be affected by their actions and take them into account when making a decision. Not having to comply with such requirements means that there is a risk that public health information campaigns may be less well informed and reasoned than other types of public act. Given the risks that were identified in TELL ME Deliverable 1.6 concerning the emission of discriminatory and stigmatizing messages this presents some important ethical concerns (that will be dealt with below in section 6). Unlike with most administrative acts, public health planners will face no legal obligation to consider the views of individuals that might be affected, representation that might allow certain forms of unintended harmful consequences to be avoided.<sup>27</sup> As a consequence, those involved in the execution of public health campaigns though, not obliged to consult and consider the views of those affected, should therefore nonetheless where possible do so in order to avoid causing harmful effects that could otherwise have been avoided.

#### *Checks on Adherence to Certain Substantial Principals of Law*

In addition to matters of legality and form, an administrative or judicial review can allow decisions or actions to be assessed for their compatibility with important constitutional or other legal principals that pertain to the decision in a substantive sense. In other words, administrative review can, in many circumstances, allow the actual decision itself to be reviewed in terms of its substantive content. Such issues go therefore beyond matters of legal authorization and form and assess a decision for its actual outcome (or sometimes its motivation). The particular legal principles that might apply are many and varied and depend upon the jurisdiction. They may for example emanate from constitutional provisions. These may for example relate to non-discrimination or non-interference with speech or the requirement of neutrality with regards to religion. On other occasions such principles may exist in specially created statutes that are designed to guide actions by the state and its officials. Such principals may even originate from international agreements such as the European Convention on Human Rights.<sup>28</sup> This latter instrument has been integrated in to the legal systems of most European States to such an extent that it can be considered to have an almost constitutional level of importance..

The non-application of administrative law to informational acts such as public health campaigns means that the process of administrative review is not available as a process that would allow the application of important legal principals to the act in question. Of most notable concern for those who may be affected by public health campaigns are those messages that may intentionally or unintentionally

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<sup>27</sup> There may of course be a moral duty and a practical need to consult individuals in the planning stages of a public health campaign. These issues are discussed further in section 6

<sup>28</sup> The potential ability of the applicability of the ECHR is discussed in section 4 of this document.

contain discriminatory or stigmatizing messages.<sup>29</sup> Given that the administrative law gateway is not available, individuals will find it difficult to apply such principals to the use of information in public health messages. This means that public health planners can use discriminatory and stigmatizing messages with little fear of consequences.<sup>30</sup> The lack of a potential check and balance in this area means that public health planners may be less concerned with acting in a discriminatory or stigmatizing way in their messages than public servants carrying out other administrative acts might be. This lack of a legal incentive means, as with issues of formality, that it is important from an ethical perspective for public health planners to ensure that messages do not contain harmful discriminatory or stigmatizing messages given that there exist few legal obstacles that can be used by individuals that may be affected by them.

### Section 3 – Summary Points

- **Administrative law and administrative procedures are important in controlling activities of the state that are capable of having effects on individuals.**
- **The use of information by the state in activities such as public health campaigns is unlikely however to be viewed as an ‘administrative act’ by most administrative law systems.**
- **This has consequences because it means that the state, when engaging in such activities will not be subject to scrutiny through of administrative review in terms of legality, important aspects of form and adherence to important substantive principals of law.**
- **This means that public health agencies have a very free hand when acting in such a manner (including in the potential use of the New Framework Model) and need pay little concern to the usual requirements that pertain to administrative acts. This will facilitate the high level of speed and adaptability that is envisaged within the NFM.**
- **A negative aspect however is that many of these requirements are associated with issues of good governance. As a consequence, a failure to consider them may mean that there is a higher chance of a negative outcome for individuals, including a higher risk of stigmatization.**

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<sup>29</sup> See Tell Me Deliverable 1.6 for numerous examples of public health messages that contain such elements

<sup>30</sup> There is however also doubt about the applicability of Human Rights Principals to purely informational acts of the type envisaged in the NFM.

## 4. Data Protection Laws and their Applicability to the New Framework Model

Unlike the areas of law described above, the rules on data protection are capable of having an impact on public health information campaigns if at any point they involve the processing of personal data. Given that the NFM foresees the use of data mining techniques at the individual level, it is likely to involve the processing of personal data. As a result, privacy data protection requirements should be considered. The most important source of such rights in Europe are the European Convention on Human Rights, the European Union's Charter on Fundamental Rights, the Data Protection Directive and various national laws. The framework that these sources provide below will be discussed below (with a particular emphasis on Data Protection Rules) and their potential applicability to the NFM.

### 4.1 The European Data Protection Framework

At the European level, data protection is recognized and protected as a fundamental right. The explicit recognition of the fundamental right to data protection can be attributed to an explosion in international, European and national legislation promulgated since the late 1970s (De Hert & Gutwirth, 2009). Such a vast body of law is codified at constitutional level in Article 8 of the European Charter of Fundamental Rights and Freedoms (EU Charter) and detailed in numerous pieces of secondary legislation. Article 8 of the EU Charter states that the processing of personal data should be surrounded with constitutional safeguards: data must be processed fairly for specified purposes, on the basis of the consent of the person concerned or some other legitimate basis laid down by law. In addition, everyone has the right of access to data which has been collected concerning him or her, and everyone has the right to have it rectified, or deleted. Article 8 also provides that compliance with these rules shall be subject to control by an independent authority.<sup>31</sup> The most important, but not the sole piece of European legislation in data protection is Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data, commonly known as the 'Data Protection Directive'. The provisions of this directive have been transposed into the legal systems of all 28 Member States of the European Union. Amongst European courts, a prominent place is also accorded to the case law of the Strasbourg based European Court of Human Rights on Article 8 of the European Convention of Human Rights (ECHR), the right to private and family life. The Court of Strasbourg has ruled that Article 8 ECHR can cover a wide range of issues such as integrity, access to information and public documents, secrecy of correspondence and communication, protection of the home, and also protection of personal data.<sup>32</sup>

### 4.2 Framework Background

Perhaps of most concern to the NFM, given its potential use of personal data are the provisions of the Data Protection Directive. The objective of the data protection framework is stated in Directive 95/46/EC, Article

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<sup>31</sup> Charter of Fundamental Rights of the European Union (2000). *Official Journal of the European Communities*, C 364, 1-22. 3 European Parliament and the Council of the European Union (1995). Directive 95/46/EC of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. *Official Journal of the European Communities* L281.

<sup>32</sup> European Court of Human Rights (2000). *Amann v. Switzerland* judgment of 16 February 2000: 'The Court reiterates that the storing of data relating to the "private life" of an individual falls within the application of Article 8 § 1 [...]. It points out in this connection that the term "private life" must not be interpreted restrictively.' (§ 65-67)

1, as the protection of: *‘the fundamental rights and freedoms of natural persons, and in particular their right of privacy with respect to the processing of personal data.’* Personal data is according to Article 2(a):

*‘any information relating to an identified or identifiable natural person (‘data subject’) [...] directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity.’*

The wide definition of personal data raises the possibility that the use of data in data mining operations envisaged in the NFM could involve the use of personal data. This may include various forms of medical data. This wide definition of health related data was for example illustrated the *Lindqvist*<sup>33</sup> case. In that case the ECJ argued that the fact that it was mentioned on an internet web site that an individual had injured her foot and was on half time leave on medical grounds constituted personal medical data.’ The processing of personal data also enjoys a wide definition, meaning:

*‘any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction.’*(Article 2(b)).

In principle, the processing of personal data in the name of legitimate interests is by default acceptable. However, it is also accepted that the free flow of personal data can be balanced against other interests and/or risks. Accordingly, the data protection framework is based on a series of *fair processing principles*, the most important of which are data minimization, having a legitimate basis for conducting processing, *respecting the rights of data subjects, and upholding the obligations* of the actors involved. Importantly for the purposes of the TELL ME New Framework model, data protection foresees that some categories of data, including data relating to the health status of a person, shall be subject to special, yet more stringent rules of communication and processing. These principals are important because not only do they form law at the European level, but they have also been transposed into the national law of EU states through domestic legislation.

#### 4.3 Data minimization

The principle of data minimization is perhaps the most central principal of the data protection framework.<sup>34</sup> The principle encapsulates a legal doctrine to referring to two key data protection principles, namely, the purpose limitation and the data quality principle (Bygrave, 2002). The purpose or use limitation, or purpose binding principle prohibits further processing which is incompatible with the original purpose(s) of the collection. Article 6 of Directive 95/46/EC foresees that personal data may only be *‘collected for specified, explicit and legitimate purposes and not further processed in a way incompatible with those purposes’*, and that such data should be *‘adequate, relevant and not excessive in relation to the purposes for which they are collected and/or further processed and ‘accurate and, where necessary, kept up to date’*. The data quality principle implies that data must be accurate, up to date, relevant and not excessive for the purposes

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<sup>33</sup> Case C-101/01

<sup>34</sup> This has been confirmed also in the Proposed new Regulation. See: European Parliament and the Council of the European Union (1995). Directive 95/46/EC. Official Journal of the European Communities L281. Article 5. *“Personal data”*, it is stated in the Proposed Regulation, must be *‘adequate, relevant, and limited to the minimum necessary in relation to the purposes for which they are processed; they shall only be processed if, and as long as, the purposes could not be fulfilled by processing information that does not involve personal data.’*

for which they were collected. Irrelevant data must not be collected and if it has been collected it must be discarded (Article 6(1)(c)).

The centrality of the data minimization principal means that it is something that the NFM will have to comply where it foresees the use of personal data. This may be particularly important where data mining is used to facilitate communications to individuals. The data minimization principal means that data can only be used for the purpose for which it was taken. Using data that was clearly connected for another purpose for data mining activities will not be permissible. This could for example occur where personal data was collected from individuals under the auspices of some other initiative, for example other public health programs. For data to be used in the context foreseen by the NFM data should have been originally collected for that purpose. One way of assessing whether this condition has been met is to look at what information was provided to individuals when they provided the data (assuming the legitimate basis for the collection of the data was consent). This issue is discussed further below. This may have potential affects on the operation of the NFM if it was to make use of individual data (perhaps through data mining) to aid the targeting of communications. This is because it may be necessary to consider the requirement of having to delete such data if requested data subjects. The exact shape of this right is however not yet fixed and, accordingly it is not yet certain what requirements will have to be met.

#### 4.4 Legitimate Basis of Processing

The European Data Protection Directive recognizes a number of conditions for the legitimate processing of personal data, namely: the *'unambiguous consent of the data subject'* and/or the fact that the processing serves *'legitimate interests pursued by private parties'* (article 7). The second relates mostly to processing that would be unavoidable under a normal commercial relationship and is unlikely to apply public health campaigns such as that described in the TELL ME New Framework model.

It is important to note that Directive 94/46/EC, (and also the Proposed New regulation) provides for a difference between the legitimate basis for the processing of normal personal data and a category it terms as *'sensitive'* personal data. Included in the categories of sensitive data are aspects such as health status and ethnic or racial background, aspects that will likely be of relevance to the new framework model and its foreseen use of *'individual data mining'*. The use of such data is associated with heightened risks in terms of privacy and discrimination. These risks, therefore, justify a regime for the circulation of health data based on general prohibition and strict conditionality. Accordingly, Article 8(1) of the Directive prohibits *'the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life'*.

Whilst this prohibition is the general rule, there exist in the following paragraphs of Article 8 several exceptions that can provide legitimate grounds for the processing of data. In having such exceptions data protection law recognizes that there may be important private and public interests in the sharing and processing of personal information related to health. Accordingly, certain derogations exist which permit processing of personal medical data. These derogations must abide by the principles of data protection, notably data minimization. In addition, as each of these are derogations from the general rule of prohibition, they must be construed in a narrow fashion and applied taking into account the concrete and real (genuine) basis on which the processing is based. For medical data these grounds include: *'the data subject's explicit consent'*, *'or'*, *'vital interests of the data subject'*, *'or'*, *'processing of (medical) data by health professionals for the purpose of preventive medicine, diagnosis, the provision of care or treatment or*

*the management of health-care services*, ‘or’, ‘reasons of substantial public interest. (Article 8)<sup>35</sup> These grounds and their potential relevance to the TELL ME New Framework model are discussed below.

### Explicit consent

The legal notion of (informed) consent relates to an important ethical principle that a person should be given reasonable assurance that she or he has not been deceived or coerced when entering in negotiation or any other purposive personal relationships (Mantovani & Quinn, 2013). Processing of personal medical data is accordingly allowed where *‘the data subject has given his explicit consent to the processing of those data.’* Consent is defined as *‘any freely given and informed indication of his or her wishes by which a data subject signifies his or her agreement to data related to him or her being processed’* (Article 7). Consent can therefore constitute a justification for the processing of sensitive data, but, in order to be valid, consent must be *‘freely given’* and contain *‘specific and informed indication of the data subject’s wishes.’* (Article 2(h)). In addition to that, the processing that a person gives consent to must respect the principles of data processing, notably data minimization. With sensitive types of data the type of consent given must be explicit (unlike other less protected categories of data where consent may be implicit).

In order to be valid, such consent must meet several conditions. *‘Free’* consent means that reliance on consent should be confined to cases where the individual data subject has a genuine free choice and is subsequently able to withdraw the consent without suffering from detrimental consequences. Consent must therefore express a voluntary decision taken by an individual in possession of all of his faculties, taken in the absence of coercion of any kind, be it social, financial, psychological or other (Mantovani & Quinn, 2013). Any consent given under the threat of non-treatment or lower quality treatment in a medical situation cannot be considered as *‘free’*. Reliance on consent should be confined to cases where the individual data subject has a genuine free choice and he or she is consequently able to withdraw consent without detriment.

The adjective *‘specific’* indicates that consent must relate to a well-defined, concrete situation in which the processing of medical data is envisaged. Therefore a *‘general agreement’* of the data subject, e.g., to the collection of his data would not constitute *‘specific’* consent. For example, nor would an agreement by a social media user that his profile data could be *‘shared with third parties for commercial purposes’*. *‘Informed consent’* means that consent by the data subject is based upon an appreciation and understanding of the facts and implications of a given situation and of any processing to be performed on that data. The individual concerned must be given, in a clear and understandable manner, accurate and full information of all relevant issues, in particular those specified in Articles 10 and 11 of the Directive, such as the nature of the data processed, purposes of the processing, the recipients of possible transfers, and the rights of the data subject. Individuals for whom medical data was taken from social or other online media would therefore have to be informed why their medical data was being taken and how it was to be processed and allowed to be able to provide consent on the basis of such information. This could have implications for the NFM (see below).

Consent must be *explicit*. This means that data subject must be aware that he or she is renouncing the special protection that Article 8 provides to sensitive data. Explicitness relates, in particular, to the sensitivity of the data. Clearly, general opt-out solutions are not acceptable, since this would allow *‘implied*

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<sup>35</sup> The Proposed Regulation, in Article 9, confirms the legal regime based on general prohibition for processing special categories of personal data and exceptions.



consent’ and thus frustrate the rationale behind the general prohibition clause. Rather, a data processor must first inform the user and obtain unambiguous and explicit consent before any data collection. This is what is known as opt-in. The requirements mean that when health data are exchanged as a part of a medical act, performed by electronic means, a patient must be made aware that he or she is sharing his medical information or that he or she is allowing others to view and process his or her health parameters. Furthermore, in some European countries explicit consent must be traceable, thus a proof must be kept, usually in written form (Mantovani & Quinn 2013). The specific rules relating to the exact form of consent can vary between the Member States of the European Union

*The Other Bases for the Legitimate Processing of Data Sensitive Data - A Limited Impact on the TELL ME New Framework Model*

The other exceptions described in article 8 of the data protection directive which allow for processing of sensitive data in vital interests of the data subject’, ‘or’, ‘processing of (medical) data by health professionals for the purpose of preventive medicine, diagnosis, the provision of care or treatment or the management of health-care services’ or ‘reasons of substantial public interest’ are arguably of less relevance to the TELL ME New Framework model as they are unlikely to apply to the processing of personal data that may be necessary.

The first of these, i.e. “vital interests of the data subject” is generally viewed as processing that corresponds with the need to treat a patient immediately and it is not possible for him or her to give consent to using his or her health information. In such instances, for example in an accident an emergency room of a hospital, it may be necessary to treat a patient (and accordingly make use of his or her medical data without waiting to get consent).<sup>36</sup> This ground for processing refers to the data subject for whom the data in question comes from. This means that the processing of a person’s data can not be legitimated because it might help others, but only where such processing may help the individual to whom the data pertains. This exception is therefore unlikely to apply to the new framework model because it does not call for the processing of individual data in a way that would directly help the individuals concerned. Even in the event of individual data mining, the likely use would not be in the vital interest of the data subject concerned, but to benefit others or perhaps society as a whole.

The second ground i.e. “processing of (medical) data by health professionals for the purpose of preventive medicine, diagnosis, the provision of care or treatment or the management of health-care services” is equally unlikely to apply to the TELL ME New Framework model. This is because this exception refers the processing of patient data within the context of an existing treatment relationship, i.e. where the physician in question has established a treatment relationship with the individual in question (Mantovani & Quinn 2013). This might for example occur where a physician, after discussion with a patient decides to run further tests on a patient and thus needs to use his data. This exception will not apply where no direct treatment relationship exists or where a physician may wish to pass patient data on to a third party (whether that third party is a physician or otherwise. It also does not apply where researchers may want to an individual’s medical data. In such instances explicit consent should be sought.

The final grounds for legitimate processing of sensitive data, i.e. ‘reasons of substantial public

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<sup>36</sup> For an in-depth discussion of these alternatives for explicit consent for the processing of sensitive data see the Article 29 Working Party Working Document on the processing of personal data relating to health in electronic health records (EHR) – February 2007 (WP 131)

interest’, concern situations where the state establishes precise legal grounds for the processing of sensitive data, including health data. This might include instances where the state establishes certain genetic databases or permits the processing of some health data to obtain an important goal.<sup>37</sup> For such processing to be legitimate however it must be precisely described in the law of the state concerned and relate to the processing of data in a manner that is clearly foreseeable and only where such processing can be justified for substantial reasons of public interest. If any of these conditions are not in place this ground for processing will not be available. With regards to the NFM, this ground for processing is clearly likely to be of little use given that communication programs (and their potential use of personal data) are unlikely to be detailed in legislation as this particular basis would require. The processing of individual health data in the context of the New Framework Model, e.g. through individualized data-mining, on the basis of ‘reasons of substantial public interest, would therefore not be legitimate.

#### 4.5 Rights of User control

The Data Protection Directive recognizes a number of subjective *rights* of data subjects. These rights include the right to be informed whenever data is collected, to access the data, to have data corrected, the right to have data deleted, and to object to certain types of processing. The purpose of these rights is to empower the user by giving him or her control over personal information. As Article 12 indicates, the data subject has the right to access all data processed about him. The data subject even has the right to demand the rectification, deletion or blocking of data that is incomplete, inaccurate or not being processed in compliance with the data protection rules. In order for individuals to be in control of their personal data, they have to be aware that data is actually collected and in the conditions to understand what happens with it data are disclosed to the service provider. For this reason, articles 10 and 11 of Directive 95/46/EC (‘information to be given to the data subject’) requires to make information about relevant events, processes, stakeholders and attributes of the collection and use of personal data to be made available in a comprehensible form to individuals concerned.

#### 4.6 A Potential Right to be Forgotten?

The 2012 Proposed Regulation<sup>38</sup> foresees further procedures for allowing individuals to exercise their rights. Amongst these exist a so called ‘right to be forgotten’ inspired largely from the concerns that surround privacy in the context of social media such as Facebook. Such issues relate to the relationship that links the right to have access and control data and the psychological and societal need to ‘be forgotten. Particularly amongst young native Internet users, there is awareness of the importance of being forgotten, which allows individuals a second chance, the opportunity for a fresh start in life (Blanchette, & Johnson, 2002). The right to be forgotten, which is one of the innovations of the Proposed Regulation, could enable people to have data held about them deleted if there are no legitimate grounds for retaining it. If the Proposed Data Protection Regulation in its current format becomes law it will mean that that users will have the right to have their data removed and halt further processing of it, even if they had previously consented to such processing. The Proposed Data Regulation is currently under negotiation between the

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<sup>37</sup> An illustrative case in this regard is *S and Marper v United Kingdom* [2008] ECHR 1581. This case involved the establishment of a genetic database containing data from those arrested in the UK. Although referring to Article 8 ECHR the court elucidated similar requirements for those required here under the public interest exception.

<sup>38</sup> European Commission (2012). Proposal for a Regulation. COM(2012) 11/4. Recital 122.



various European Institutions.

#### 4.7. Implications for TELL ME New Framework Model

The New Framework model foresees a role for individualized data mining in order to assess likely behavior of populations, (and the individuals that comprise them) in the context of a pandemic<sup>39</sup>. Such processing might conceivably involve the extraction of personal data from online media, including social networks. This may involve the use of personal data and even in some occasions of sensitive personal data (including that pertaining to health and possibly even ethnicity). The purpose of obtaining such information would be to allow communication (*inter alia* encouraging vaccination uptake) to be targeted at groups and even individuals in society rather than sending one message to society at large, as has traditionally been the case. Where doing so involves the collection of personal data, the data controller will have to respect the applicable principals of data processing. This will include the need to have a legitimate purpose for such processing and also the need to meet the data minimization principal. Where such processing involves sensitive personal data i.e. involving health related information or other aspects such as race or ethnicity the conditions are particularly strict. In such conditions, the more onerous conditions for processing of sensitive data (Article 8 of the Data Protection Directive) will have to be met.

The most relevant of these for the NFM is consent. Securing such consent for mining of online and social media may pose difficulties. This is because public health authorities (who would conduct such data mining operations) would not be able to contact all relevant individuals beforehand in order to obtain consent. The likelihood is rather that such data will be acquired from commercial third parties that host the data in question. This may include the operators of online and social media (e.g. Facebook twitter etc.) Such operators often make their users agree with complex privacy policies that permit user data to be shared with commercial parties (Wang et. al. 2011). With such permissions operators are able to sell commercially interesting user data to commercial organizations that make use of them, usually for advertising purposes. In Europe, where data protection legislation is fairly strict (i.e. under the auspices of Directive 94/46/EC) such operators must have consent from individuals for such a transfer of data. Consent is usually provided by ticking boxes on consent forms when signing up to accounts on the platform in question. The information provided in such consent forms is usually very general, specifying perhaps that data may be shared with interested third parties including for commercial purposes. Such generic consent policies that usually relate to the possibility of handing data over to advertising agencies and other similar organizations may be difficult to reconcile with the transfer of data to public health authorities for use in targeted communications in pandemic organizations (as envisaged in the NFM). Given requirements that consent should be specific, it is difficult to see how consent given through such generic online forms for the use of data by certain third parties on a commercial basis could be considered as sufficient to warrant a transfer as envisaged under the NFM. Where the data in question is considered sensitive under Article 8 of Directive 94/46/EC) the demands are much more strenuous. This might occur, for instance, where data mining techniques wished to incorporate information pertaining to aspects of individual health characteristics or data pertaining to racial or ethnic status. Such data could conceivably be useful in identifying and targeting ‘at risk groups’ (in terms of being infected or infecting others) or groups that may be resistant to vaccine uptake. As discussed above, the communications models such as the NFM would, in using such data, have to rely upon gaining explicit consent or claim that such processing was for ‘reasons of substantial public interest.’ The second possibility could only be met where public bodies were clearly

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<sup>39</sup> See Deliverable 3.1 – New Framework Model For Communication, page 10

authorized in legislation to carry out processing concerned and where such legislation was clear and precise enough to allow such legislation to be visible. This is unlikely to exist in most cases, not least because it would be very difficult for a public health organization to know what type of processing might be required in advance of a pandemic.

However, obtaining consent from all participants in a meaningful way, that will allow useful data to be collected, is no simple, or perhaps even feasible task (Verschuuren et al. 2008) In particular, there exists the requirement that explicit consent be ‘informed’. This relates to a desire in the data protection framework to ensure autonomy for data subjects in deciding whether they allow processing of their sensitive data. In particular it means that in order for consent to be valid, individuals must be informed of exactly what is to be done with their data and by whom.<sup>40</sup> Failure to provide any such information would invalidate consent render any processing illegal.

It remains difficult to see how any public health authorities could secure truly informed consent as envisaged in the NFM (Verschuuren et al. 2008). This would be especially true where public authorities have acquired information from online social networks in a manner similar to how most commercial third parties operate. This is because the electronic consent forms provided to users joining such networks (and the information provided to them) are unlikely to contain specific information describing such uses of data. Given this the use of such information in a manner envisaged by the New framework Model risks being considered as illegal under the EU framework on data protection, both in terms the act of a social network passing sensitive data to a third party (e.g. a public health body) and the processing that such a body would carry out later.

#### 4.8 Anonymization as An Alternative for the New Framework Model

One possibility for the operation of the NHM is to rely on anonymized data in its data mining operations. Anonymized data represents data that cannot be linked to an individual. Anonymized data would therefore be data that previously referred to an identifiable person, but where that identification is no longer possible.<sup>41</sup> The use of anonymized data is attractive in that it means those using the data will not have to apply the provisions of the Data Protection Directive. This concept was recently confirmed by the authoritative Article 29 Working Party created by the Data Protection Directive where it stated that *“Anonymized data do fall out of the scope of data protection legislation .... Once a dataset is truly anonymized and individuals are no longer identifiable, European data protection law no longer applies.”*<sup>42</sup>

There are however major difficulties associated with the creation and use of anonymized data. Most notably the processes required for rendering a data set truly anomalous can render the data set of little use. This may be an issue for the NFM which foresees ‘individualised data mining’, allowing individuals to be targeted with communications on an individualised level. Such activities would obviously be impossible with truly anonymized data as it would longer be possible to make a connection between the data set and individuals. The use of anonymized data might however allow some useful operations for the NFM. In particular the use of anonymized data could allow aggregated searches and enquires to be performed. Such information might allow predictions to be made about certain groups in the event of a pandemic, but

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<sup>40</sup> See the Article 29 Working Party Working Document on the processing of personal data relating to health in electronic health records (EHR) – February 2007 (WP 131)

<sup>41</sup> See Article 29 Working Party Opinion 4/2007 on the concept of personal data

<sup>42</sup> See Article 29 Working Party Opinion 05/2014 on Anonymization Techniques

would not allow individuals to be identified.

#### **Section 4 – Summary Points**

- **Data protection legislation applies where personal data is processed. In Europe the most relevant source of law is the Data Protection Directive which has been transposed into the Laws of all EU Member States.**
- **This regime may apply to the TELL ME New Framework Model if it opts to use personal data in data mining strategies (in particular if such strategies are targeted to the individual level).**
- **In the event that such strategies are used, any communication program would have to comply with important legal principals such as data minimization and having an adequate legal basis for consent.**
- **The latter will present difficulties where such data is extracted from online platforms such as social media. This will be particularly true where sensitive data such as health data is used, where the rules concerning explicit consent are particularly strict.**
- **One possibility to avoid the stringent requirements of the European data protection regime is to use anonymised data, i.e. data that can no longer be linked to specific individuals. A disadvantage with such an approach however is that the usefulness of such data may be limited.**

## 5. Freedom of Information

Freedom of information laws represent one type of law that may allow private individuals to gain traction with purely informational activities such as public health information campaigns such as that envisaged by the TELL ME New Framework Model. Freedom of Information (FOI) Laws allow individuals to request a copy of information held on a range of matters held by the state or entities that carry out a public function (Bannisar, 2006). The type and breadth of FOI law varies from state to state, with some states having no law, others allowing individuals to request copies of information on specific activities whilst some states even allow individuals to request any stored information (with some key exceptions) held by the state (Mendel, 2008). The potency of such techniques was recently shown by researchers in the UK that were able to request a film that would have been used in the event of a catastrophic influenza pandemic, information that the relevant public bodies did not wish to be released into the public domain.<sup>43</sup>

### 5.1 Historical Background

FOI laws are a mainly modern phenomenon, though there were some important historical developments that were symbolically important (Bannisar, 2006). These included provisions in the 1789 French Declaration on the Rights of Man which allowed individuals to request information on the budgetary matters of the states.<sup>44</sup> Some early provisions also existed in the US and were associated with a desire to see a greater level of transparency and openness in governance than had existed under British rule. Sweden seems have been the first state to have had something resembling modern FOI in the late eighteenth century with the adoption of its Freedom of Press Act in 1766.<sup>45</sup> Finland and Columbia were other unusually early adopters of FOI laws.

The Universal Declaration of Human Rights, created at the closing of World War 2 supported the notion that all individuals should a general right to receive information.<sup>46</sup> Two decades later the USA served as a pioneer and an example that would be followed by many states in subsequent decades.<sup>47</sup> Its FOI Act created in 1966 has been upgraded and expanded several times since then.<sup>48</sup> Followers included most European States that have created expansive FOI laws in the process of their transition from Communism to market based democracies. Adoption has also been strong in Latin America with many states there having adopted FOI provisions. Progress on FOI laws has however been weaker in Africa and Asia. A gradual trickle of followers has turned in recent decades into a torrent, with most western democratic states now possessing some form a FOI legislation. Nearly all European states now possess such laws.

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<sup>43</sup> <http://www.bbc.co.uk/news/uk-politics-13665149>

<sup>44</sup> The declaration states “All the citizens have a right to decide, either personally or by their representatives, as to the necessity of the public contribution; to grant this freely; to know to what uses it is put.” Quote taken from (Bannisar, 2006)

<sup>46</sup> Article UHDR 19 speaks of a right to ‘receive information

<sup>47</sup> An important actor for the promotion of such activities has been the Open Society Institute founded by business man George Soros. More information can be found at <http://www.soros.org>

<sup>48</sup> Norway and Denmark were early followers of the FOI trend adopting laws in 1970. France and the Netherlands followed in 1978, Australia and New Zealand in 1982 and 1983. The UK adopted its Freedom of Information Act relatively late in 2001.

## 5.2 Variations in FOI – Its Possibilities and Limitations?

### What Does FOI Allow?

There is a great deal of similarity between FOI laws in varying countries. This high level of similarity comes because many states have modelled their FOI systems on one of a few model examples.<sup>49</sup> Most systems of FOI apply to the executive and administrative parts of the state. This means the political leadership at the top and the bureaucratic machinery below it (Bannisar, 2006). This will usually therefore include ministries and department of health and the bodies created under their auspices designed to carry out a public health function. Some systems may have a list of bodies that such laws apply to whilst other may simply specify that all state or public institutions are covered by FOI laws. The latter is more broad-reaching because in most countries, new governmental bodies are created all the time. This is particularly so in the case of public health where new bodies may be established frequently to deal with arising issues of public health. FOI laws are usually limited in terms of the power of access they grant over private bodies. In some states FOI laws may however grant access where certain private bodies have been granted the right by the state to carry out a public function e.g. utility companies. Older FOI laws refer to items such as records, official documents or files (Bannisar, 2006). Whilst this may include much government information there are many categories that might not fit in. This may include commissioned scientific studies, policy discussions, emails, etc. For these reasons many of the state that adopted FOI laws later simply refer to a right to ask for ‘information held by the state’.

### Limitations to FOI

In many states reference is made to information that is recorded or stored in some manner. It may not be possible therefore to uncover what was discussed at meetings where no record was kept or during other types of internal conversation or discussion. Some states do not recognise a right to view documents that discuss the formation of policy. States such as Ireland do not allow information relating to decisions to be accessed until after a decision has been made.<sup>50</sup> In many states there may be restrictions to papers that pertain to discussions between the highest level of authority, e.g. the executive.<sup>51</sup> Such provisions will often stay in place for a number of decades.<sup>52</sup>

In addition to such high level exemptions, most states also recognise exceptions for material that may for one reason or another be deemed too sensitive to be released to the public. This may include, for example, material related to diplomacy, national security, information that would cause harm to individual privacy interests (e.g. personal records).<sup>53</sup> In addition to such pre-defined categories many FOI systems may also provide for a public interest test<sup>54</sup>. Such a test can be applied in order to discern whether releasing the

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<sup>49</sup> Freedom of Information From Around The World: A global Survey of Access to Government Information Laws - A Report for Privacy International. (2006). Banisar sites for example Canada and Australia, which act as examples throughout the common law and English speaking world.

<sup>50</sup> This is for example the case under Irish FOI requests.

<sup>51</sup> In the UK exceptions exist pertaining to Information relating to the formation of government policy, communications to, from and between ministers, legal advice to the government, and the operation of any ministerial private office. See **Freedom of Information Act 2000 s35**.

<sup>52</sup> In the UK for example cabinet documents are secret for thirty years. Whilst in Ireland this figure is ten years. In countries such as New Zealand no such provisions apply as cabinet papers are often released immediately. See; Freedom of Information From Around The World: A global Survey of Access to Government Information Laws - A Report for Privacy International. (2006).

<sup>53</sup> In Ireland for example police records are not open to FOI queries.

<sup>54</sup> Under the UK's Freedom of Information Act (2000) for example there are 24 different types of information for which a public interest test can be applied for example.

information concerned would be in the public interest. In doing so administrators must decide whether the potential harms caused in releasing the information would be in the interest of the public. Such harms might for example include harms to the reputations of individuals, groups, or the state in general. Another possibility might involve maintaining public order.<sup>55</sup> If the legislation in question provides for such a test, and an administrator feels that it would not be in the public interest, such information can be withheld from the public, even where it is has been directly requested.

### 5.3 Relevance of Freedom of Information Laws to the TELL ME New Framework Model

FOI requests have the ability to have an important bearing on public health information campaigns, including that envisaged by the NFM. This is primarily because they provide individuals with the ability to compel a certain level of transparency on those who run such campaigns. The availability of such laws (in jurisdictions where they apply) should be considered by the planners of public health information campaigns when deciding upon whether to release or withhold certain pieces of information that may be in their position.

Often, in deciding upon such information, public health authorities will have to decide upon whether such information is likely to forward or increase the information campaign they are involved in. In examples such as the NFM such a situation might exist for example where public health authorities are considering releasing information relating to the efficacy or effectiveness of a vaccine (or possible a lack of available data on such issues (Osterholm, 2011)) or the effectiveness of other simple methods of hygiene control such as washing of hands and wearing of face masks etc. At certain moments, public health officials may not want to emphasise or even acknowledge certain pieces of information that could be considered capable of undermining their campaign. Imagine for instance a campaign that is trying to promote the uptake and acceptance of a vaccine for a pandemic influenza outbreak. The vaccine will likely have been very recently synthesised and it is unlikely that any data will be available of its effectiveness. Despite this, it may still represent the best method to tackle the spread of the virus and the harm that it causes (Glick, 2007). As a result of this those involved in the communication of public health messages might not want to emphasise or even admit such a lack in knowledge for fear that it might actually harm the effectiveness of their campaign.

Whilst such a decision might make some sense in a broad public health management context, in which the primary concern is to minimise the impact of the disease in question, it appears dubious when viewed in the light of the important medical ethics and human rights concept of autonomy.<sup>56</sup> Such a notion suggests that individuals should be free to choose what treatment options they pursue in the light of whatever information is available. The ability of FOI laws to give individuals the power to request such information reflects this. It is important therefore for the organisers of public health campaigns to bear in mind both the moral duty of transparency that exists and also a legal duty to provide such information when making decisions. Given the possibility that freedom of information requests may be used by individuals to uncover information that would not otherwise have been released, it is important for public health planners to consider the consequences that will occur if information (that would otherwise not have been released) is uncovered at a later date. Such an event is likely to result in harm to the level of trust that individuals feel towards the public health campaign in question and possibly give rise to various conspiracy

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<sup>55</sup> See for example s38 of the UK's Freedom of Information Act (2000)

<sup>56</sup> These issues were discussed in TELL ME Deliverable 1.6

theories. Such requests could, depending on the legislation available be lodged at any time and could have various effects both before and after a pandemic has occurred.

### Before a Pandemic

As the New Framework Model makes clear, preparation for communication during an influenza pandemic (or any other serious public crisis) should be in progress long before the actual crisis begins.<sup>57</sup> This phase will involve various aspects of decision making and information gathering that could be prone to FOI requests. This includes decisions of strategy, including plans on which stakeholders to involve, what methods of communication to use, and potentially advice in terms of treatment for those that fall ill (e.g. whether to go to one's GP or hospital or stay at home.) Such information will likely exist in various forms but will be held by public health authorities and possibly open to FOI request. As described above, the availability of FOI request adds a practical dimension to the moral dilemmas concerning the release of information that may be perceived as not being conducive towards the overall aim of the information campaign. If individuals uncover information that was released it may reduce levels of trust, possibly reducing the effectiveness of communication once (or if) a pandemic starts. Public health planners should also be aware that such requests could be used to uncover information that, although not hidden, may have been intended only to be released at a latter date. This may include information videos or other messages that are intended only to be released once a pandemic occurs. Indeed this recently occurred in the UK where researchers were able to uncover a video message that was intended to be used in the event of a catastrophic influenza message.<sup>58</sup> The pessimistic tone that was used in the message was particularly striking, and could perhaps give rise to fears amongst that public that there is little public health organisations can do in the event of a pandemic. This video has subsequently been disseminated throughout the internet and social media. Such issues could make public health messages less effective when a public crisis actually does occur.

### (ii) During a pandemic

The situation during a pandemic will likely be much more confusing than that which exists either before or after. During a pandemic the situation will be in a state of flux and the facts of the situation at hand may not at all be clear. In addition, public health bodies are likely to be operating at full capacity and resources in terms of personnel will likely be stretched to breaking point. As a result, public health bodies will justifiably have little ability to answer freedom of information requests during a pandemic. This may be both because they do not, as of yet possess any real information on the pandemic in question and also because they simply do not have the ability in terms available personnel to handle such requests. Systems of FOI information laws often seem recognise such situations by allowing time fairly lengthy time periods for which public servants are permitted to answer such requests and also the possibility to ignore such requests in times of severe crisis (Bannisar, 2006, (Mendel, 2008). In addition, FOI laws may require precise formulations of what is requested and not recognise general requests for any information held on a subject. Such formulations may take time and knowledge to create (often being used for example by journalists or academics that are usually more well informed on a subject than a member of the general public). The availability of such time or knowledge may not exist in the midst of a pandemic situation

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<sup>57</sup> See TELL ME Deliverable 3.2

<sup>58</sup> <http://www.bbc.co.uk/news/uk-politics-13665149>



where, to begin with, there is little knowledge available and where the situation can be categorised by rapid changes in events and understanding. Given these issues the use of FOI during the active phase of a pandemic is likely to be limited.

(iii)After a pandemic

FOI requests may also be able to secure the release of information in the post pandemic phase. In doing so individuals may be able to uncover information about the availability of information and decisions taken during the pandemic. This has the potential to expose both errors that were made in terms of decision making and also the information that was available at the time. Given the nature of a pandemic or any other serious public health threat as an event that is unpredictable in nature and difficult to plan for, there will no doubt be errors in overall strategy, that though easy to see with hindsight, might have been difficult to avoid at the time. Public health planners have to be aware that FOI laws mean that individuals (including highly motivated journalists and academics) will have the possibility to discover such errors. This could occur for example with requests for information pertaining to scientific advice that had been received or to decisions to change strategy in the light of new information. Even where decisions were made in good faith and with the best available individuals at the time, it is often easy (given the receptivity of the press) to describe such mistakes consequently as being indicative of incompetence or even sinister motives that were not in the interest of the general populace. Indeed as history has shown there is often a large public appetite for information demonstrating the incompetence of public health authorities or their bad intentions in times of crisis. In the aftermath of the H1N1 pandemic in 2009 much public and media attention has for example focused on the ‘overselling’ of antiviral drugs that were brought in great quantity by many states (Jack, 2014). The availability of the internet and social media appear to provide an ever fertile soil for such sentiments and increase the ease with such reports of malpractice can be disseminated. Indications that public health authorities had intended to keep such information from public eyes are likely to increase the negative perceptions surrounding such information and harm feelings of trust through a perception of attempts to avoid transparency. Given these risks, public health authorities should be aware that FOI legislation increases the risks of keeping information from the public and the harm that the later discovery can pose to trust in such authorities. Even where such an occurrence takes place after a pandemic has subsided, there exists the potential that public trust in the actions of public health authorities will be eroded with negative consequences for the effectiveness of communication strategies in subsequent public health crises.

Given the harms that can occur through the discovery of information that was not intended for public release, FOI can be thought of as a legal mechanism that encourages a greater level on transparency on the part of public organisations, including public health bodies (Berger 2011). In particular they encourage the proactive release of information to the public on an on-going basis. They reduce the temptation and effectiveness of simply not realising information as a means of hiding uncomfortable truths from the public. The NFM through its emphasis on an on-going conversational approach with stakeholder should allow the facilitation of such a proactive approach to transparency. Doing so will allow changes in strategy and reasoning to be explained continuously to the public (including *vis-à-vis* stakeholders). Whilst this might prove problematic on occasions where it highlights errors in previous strategies and knowledge, it is likely to prove less damaging than the harms to trust that can occur where information is discovered later, giving the impression that it was not ‘for public eyes’ (Glick, 2007).



## Section 5 – Summary Points

- Freedom of information laws allow individuals to request various forms of stored information from the state and its various bodies.
- The exact types of information that can be requested vary from state to state but often include most types of recorded information, including scientific documents and data that may be available.
- There therefore exists a risk that private individuals will be able to uncover information that had not been intended for public release (e.g. because it may be frightening or may call into question the effectiveness of various treatments). Where this happens the overall level of trust in public health strategies may be damaged
- The existence of FOI regimes therefore act to encourage as high a level of transparency as possible, including in public health campaigns as envisaged in the TELL ME New Framework Model.

## Part 2 Ethical and Political Issues Surrounding the Use of the New Framework Model

### 6. Public Health Communication is Less Focused on the Individual and More on the Collective – Risks for Individuals and Groups

As TELL ME deliverable 1.6 discussed, the ethical obligations of medical authorities are conceptualised differently in matters of public health communication. In the conventional medical situation, ethical dilemmas usually relate to the how a physician should treat a patient or a defined group of patients. Even where discussions relate to groups of patients, the focus is very much on the obligations of physicians to individual patients and the rights that individuals should expect in their treatment. This is different than ethical discussions concerning the provision of medical care to patients where rights of the individual are central and ideas such as autonomy are prominent (Beauchamp & Childress 1994, Gillon 2003, Peel, 2005). In public health communications however obligations are usually thought of as existing to society as a whole or perhaps certain communities that for one reason or another may be affected by a public health threat e.g. outbreaks of influenza. In such a context effects are rarely on single individuals or rarely gaged, with the focus usually being on the effect on society in general or particular communities. In many respects the legal situation described above also reflects this; creating a situation whereby individuals have little power to influence the use of information by public health bodies, including in context of an epidemic. Given that (as deliverable 1.6 discussed at length) public health messaging is able to bring about a series of harms to certain groups of the public or exacerbate problems that already exist in society, this is concerning (Guttman & Salmon, 2004). Such harms can include the stigmatisation of various at risk groups and the fostering of an environment that is conducive to discrimination (Link & Phelan 2006). Such effects can bring about harmful effects such a health care avoidance and worsen the position of already marginalised groups in society. The potential for such effects demonstrates that the cost of misused responsibilities in terms of public health communication can be sizeable and that it is inaccurate to think of such powers as being harmless.

The lack of potential legal protection from areas of law that are usually available to provide protection from actions of the state or other public bodies means that informational activities, as envisaged in public health campaigns, will not be subject to the same level of control on the part of individuals that are affected by them. Individuals who feel stigmatised by a public health information campaign will not be able to challenge such campaigns in court, or assert that they do not meet certain formal requirements that are usually associated with administrative acts (e.g. a duty to consult or give reasons, see section 3 above). This lack of power on the part of individuals to hold public health planners to account means that such individuals are likely to feel less pressure to ensure that their activities do not unnecessarily pose harm to individuals. This lack of pressure to ensure that one's actions are as harm free as possible brings with it both ethical concerns and responsibilities. These stem from the lack of potential restraints on the power of individuals and mean that those involved in such campaigns face an added responsibility to consider thoroughly the potential impact of their activities. In particular those involved should be attentive to the lack of the application of the normal formal requirements on administrative activities (E.g. prior announcement, consultation, the provision of reasons for decisions, and a duty to review decisions subsequently). Given that such requirements are associated with practices of good governance (Aronson, 2004), public health

planners should, as far as possible, ensure that such elements exist within their communication programmes, even where there is no legal obligation to do so. Possibilities for incorporating such practices are discussed in the following section.

### **6.1 An Ethical Duty to Include Practices of ‘Good Governance Practices Within the New Framework Model**

Even though (as discussed in section 3) the NFM is likely not required to by law to do so, it’s design means that it allows for an incorporation of some of the practices of good governance described above. An analysis of the model shows that it could facilitate complying with such principles. In particular the high level of interaction with the public and numerous stakeholders is important. In this context an emphasis on interactivity with the public is likely to both promote aspects of good governance and increase the effectiveness of the communication efforts in general.<sup>59</sup> Close connections with such stakeholders, in particular, using social media will allow potentially affected parties to make representation at important junctures in the process of public health communications. In terms of an influenza pandemic this will allow affected individuals the ability to communicate their thoughts and concerns about the public health communications strategy before during and after an epidemic has occurred.

#### *Implementation of Good Governance Principals in the Pandemic Planning Stage*

A stakeholder based, interactive process as envisaged in the NFM will allow individuals to communicate their concerns regarding the potential strategy to be used in the event of a pandemic during the planning stages. This will include aspects that could foster stigmatising or discriminatory behaviour. The NFM allows public health planners to react to such consultation in an interactive manner. In addition it also allowed public health planners the possibility to provide adequate reasoning for their choice of strategy and message beforehand. Such explanations can reduce doubt in the minds of the public in general and also certain communities that may be more concerned than others. The provisioning of reasoning and other explanatory material, will also allow a greater degree of transparency and scrutiny by potentially affected groups before the event of pandemic than would have been possible under older more static models of communication. In addition, the availability of reasoning and the availability of information could serve to reduce rumours that exist due to uncertainty (Glick, 2007). By allowing such an interactive process of scrutiny before a pandemic arises, a communication programme such as the NFM could be able to avoid the worst instances of stigmatisation and other negative effects that have been associated with public health communication in the past.<sup>60</sup>

#### *Implementation of Good Governance Principals in the Pandemic Planning Stage*

An interactive process will also allow for a form of consultation that continues if a pandemic has occurred and a public health communication strategy is in full flow. This is important because it is impossible to

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<sup>59</sup> The WHO has furthermore stipulated that it views such interaction with stakeholders to integral to meeting the obligations of states to build their core components for responding to epidemic threats see: IHR Core Capacity Monitoring Frame Work -Checklist and Indicators for Monitoring Progress in the Development of IHR Core Capacities in States Parties April 2013 WHO/HSE/GCR/2013.2

<sup>60</sup> For more discussion in this area see TELL ME Deliverable 1.5 – Report on Narratives and Urban Myths

predict the exact nature and context of a pandemic before the event occurs. As a result it will be necessary (at least to a certain extent) for public health planners to react to events as they occur. This will involve tailoring public health messages to events that were unpredicted and may be fast changing. In doing so public health bodies may have to use messages and issue information that were not foreseen beforehand (Gerwin, 2012). These unforeseen messages and information will carry with it a risk of containing material that may be conducive to stigmatisation or discrimination. This risk will be heightened because potentially affected communities will not have been able to have known about the use of such material beforehand and have had the choice to consult with public health planners concerning aspect that had the potential to cause harmful effects for their communities. An interactive strategy such as that envisaged in the NFM will however allow individuals and communities to provide feedback during the course of a pandemic event, including concerns over elements of messages that may be conducive to a stigmatising or discriminatory environment. Such feedback will allow public health planners to adopt their message when necessary, reducing the potential negative impacts of their messaging as much as possible. In this manner the NFM represents an advancement on previous more static and less interactive models that would have been less open to real time feedback on the negative effects that their messages may have produced.

#### Implementation of Good Governance Principals in the Post-Pandemic Stage

In a similar manner a high level of interaction with stakeholders from affected groups following a pandemic will allow such groups to convey any negative experiences concerning the public health messaging that they were suspect to. Whilst this will not be able to erase any problems that have already occurred, it will allow problem areas to be identified and improved for campaigns for future public health emergencies. Processes of continued consultation (as envisaged in the New Framework Model) can provide public health planners the opportunity to learn lessons from each pandemic and implement them into their plans for future responses to public health issues. In addition to this post pandemic initiative, consultation will allow public health planners to identify areas where stigmatising rumours and myths have risen and provide further information to the public that might be able to reduce such problems. This could be useful for instance where knowledge vacuums at the time of the epidemic have given rise to unfounded rumours of a stigmatising nature (Gerwin, 2012). This can be common to outbreaks of infectious diseases where rumours may arise surrounding the origin of a diseases and groups and behaviours that may represent an increased risk in terms of transmission (Barry, 2004)<sup>61</sup>.

#### **Section 6 – Summary Points**

- **The lack of engagement of administrative laws with informational acts such as that envisaged in the TELL ME New framework model creates concerns in terms of a lack of incentive to implement practices associated with good governance.**
- **Such practices include prior announcement of policy, consultation, the provision of reasons to explain decisions and efforts to review decisions after they have been made.**
- **Despite the lack of legal compulsion, such practices should be at the heart of the TELL ME New Framework model during the pre, during and post pandemic phases.**
- **Fortunately the New Framework Model appears to facilitate such activities through its emphasis**

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<sup>61</sup> The *cause célèbre* of such Rumours is the 1917 Spanish Flue Pandemic. The link with a Spanish origin was however only based on incorrect rumours that were circulating at the time.

**on the use of interactive forms of online and social media to communicate with various stakeholders.**

## **7. Issues Surrounding the Use of Non-State Entities as Integral Components of Public Health Messaging**

The New Framework Model is innovative in encouraging a multipolar approach in which public health bodies are but one important aspect in disseminating affective public health messages to the public. The NFM foresees much more interaction and use of other stakeholders in the targeting and dissemination of public health messages during an influenza pandemic. This represents a change from more traditional models of public health communication that viewed the process in a much more hierarchical manner whereby public health agencies would attempt to disseminate their message to the public in general. The NFM accordingly aims to make use of a range of stakeholders that represent and have connections to various groups. The multi-level involvement of such a variety of stakeholders has been recommended by the WHO as something necessary to meet a state's 'core requirements' in terms of pandemic preparation.<sup>62</sup> Given such associations, it is hoped that such stakeholders will represent effective partners in the targeting and dissemination of messages to groups before, during and after a pandemic. The NFM therefore represents to a certain extent a shift from an expectation that the state or other public bodies would be solely responsible for the planning and execution to public health communication to a situation where non-state entities occupy a central role in such activities (Reynolds & Seeger, 2005). Whilst such a transfer of expectations might allow for improvements in the targeting, formulation and dissemination of messages, it presents certain ethical concerns in terms of the accountability of non-state bodies that will be involved in carrying out functions that carry enormous importance for the public as a whole (given the context of a influenza pandemic)

### **7.1 The Accountability Gap**

Whilst sections 3 and 4 of this document may have already established that there are limited judicial limits on public acts of a purely informational nature, this does not mean however that there are no restraints whatsoever. There still exist, in most cases, a level of control on the part of the executive over the various public bodies under their remit. In the context of public health communication this usually means that ultimate control will rest with a minister of health (or some other equivalent in the executive) who will usually be accountable to a legislature that carries with it the stamp of democratic legitimacy. In such an orthodox arrangement ministers or the executive as a whole would be expected to bear ultimate responsibilities for any failures of their respective department. He or she would be expected to correct or change matters so that problems were resolved (Craig, 2012). Such members of the executive are usually able to direct public servants to act in a manner that fits with their policy vision (so long as such a vision is within the limits of the law). In addition, the executive may often have the power to fire or transfer personnel or to cut funding for certain programmes. Where it is perceived that the executive has not carried out its function properly a legislature may be able to demand the resignation of a minister and as a ultimate resort vote down an executive in a confidence vote (Dowding, 2005). This level of control is however admittedly weak, especially in comparison with judicial methods of control. Legislatures often do not have the ability to control minute aspects of departmental spending or organisation. As a result government departments are often free to organise themselves in a way they see fit (so long as they are

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<sup>62</sup> IHR Core Capacity Monitoring Frame Work -Checklist and Indicators for Monitoring Progress in the Development of IHR Core Capacities in States Parties April 2013 WHO/HSE/GCR/2013.2

within the law) and run programmes how they wish (so long as they stay within their overall budget allowance. The extreme and blunt nature of this legislative ‘stick’ means that it is rarely used (Craig 2012). Parliaments (that are normally composed of parties in government) are unlikely to bring down governments because of the harmful results brought about by one spending programme (for instance a public health campaign).

As tenuous as parliamentary control through the executive is, where it exists it can be seen as giving a sense of democratic legitimacy to activities carried out by the state. This is because parliaments are elected by the populace and parliaments usually approve or limit the executive which is tasked with carrying out government activities. This arrangement provides (a weak) link and lever of control that stretches from the electorate to the state and its bodies in the actions they perform. Whilst it might represent a very weak form of control in comparison with judicial controls (especially for minorities), such parliamentary control does at least provide some technical level of control and a basic level of democratic legitimacy (Issacherof, 2004).

Such a level of control does not of course exist for private organisations. They are not accountable to the electorate as public organisations are, at least indirectly through the ballot box. This can present concerns where private entities are tasked by the government with carrying out functions that have a public interest. Given the extensive reliance of NFM on pseudo-state or non-state actors there therefore exists concerns around issues of accountability. Such problems do not mean that co-operation with private entities is unwanted, such partnerships offers the chance combining a greater range of expertise and logistic capabilities than would otherwise be possible (Buse & Harmer, 2007). Despite such benefits it is important to be aware of problems that can occur in instances of such public private partnership in public health and, where possible, take measures to reduce the risks associated with them. Such problems include issues described in the following sections.<sup>63</sup>

## 7.2 Non Alignment of Interests of the Various Parties

This issue relates to the fact that the various partners involved in a public private partnership of the type envisaged in the NFM are likely to have different aims and ambitions (Buse & Harmer, 2007). Such a variation will often relate to the very nature of the stakeholders that are involved, including what interests and individuals they represent. Public organisations such as governments and international organisations often will have very general aims of reducing the severity of the impact of any pandemic on global society as a whole. This will involve an aim to reduce the level of infections to as low a level as possible and to vaccinate selected groups to as high a level as possible.<sup>64</sup> Such aims may be very different for stakeholders that have been created to represent various interest groups such as minorities or healthcare workers for example. Such stakeholders have been created to represent the interests of narrowly defined sections of society. Their aims in taking part in pandemic communication frameworks are primarily to protect the groups that they represent. It is possible that the interests of such groups may differ from the interests of society as a whole. Groups representing healthcare workers may for example feel that it is in the best interests of some of their members to avoid certain types of situations e.g. coming into contact with certain individuals, making home visits etc., even though national and international entities might see such

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<sup>63</sup> Most of these issues are well described in (Buse & Harmer, 2007)

<sup>64</sup> Even amongst such public entities there may be some difference with particular national entities being more concerned with the impact of a pandemic on their territories than in other countries for example.



activities as being in the best interests of society overall. In a pandemic situation there is therefore a risk that the communications of such stakeholders to the group its represents may not be 'in sync' with what which national and international organisations might desire.

This issue is of course not restricted to not-for profit interest groups that represent certain sections of society. It also applies to private profit seeking organisations such as pharmaceutical organisations that are included in the NFM. Such organisations will be concerned with engaging in profitable activity as their primary motivation. For pharmaceutical companies this will involve maximising contracts and sales of medications and vaccines. The perception of such motives has been acute amongst the general public in latter years, not least helped by strong sales of antiviral medicine to many states in the H1N1 pandemic of 2009, a pandemic that proved to be much less virulent than expected (Jack, 2014). Given such commercial motives, there exists the risk that private entities will tailor their communication efforts to maximise their profit. This might include, for example, communications that over-stress the severity of a particular virus and its effect on individuals, or statements that overplay the effectiveness of vaccines or treatments such as antivirals. Whilst the range of the varying interests of stakeholders involved in complex public-private partnerships can bring new capabilities in terms of the ability to reach diverse groups with communication, the diverse interests that such groups possess brings a risk that the central public health message may become confused through the various private interests that exists. There also exists the possibility that individuals may be distrustful of the overall message due to the perceived over influence of certain private stakeholders e.g. pharmaceutical companies.

### **7.3 Lack of Fair representation amongst private stake holders**

A further potential problem in global health partnerships that involve a mixture of private and public entities is that a disproportionate role and level of responsibility can often be given to large commercial entities, often in contrast to other entities such as community groups. This can create problems for the effectiveness of a partnership where diversity of stakeholder representation is important in achieving as wide a level of participation with society as possible (Global Health Partnership, 2004). Previous experience has shown that it is important to ensure the right balance of people with the right skills and experience are represented, including not only people making decisions, but those affected by them. There exists the risk that large commercial organizations will be able to lobby more effectively for inclusion in healthcare communication projects such as that envisaged in the NFM because they have more resources and consequently a louder voice. Where this happens the result may be that more vulnerable and marginalised groups find it harder to achieve inclusion as a stakeholder. This may mean that already marginalised and disadvantaged groups become further estranged through public health communication, something that is both ethically dubious and also concerning from the point of view of a program's effectiveness. It will therefore be essential to attempt to avoid or at least minimise such problems in the planning stage of an epidemic. In doing so it will be important to be aware of such risks and make pro-active efforts to understand and engage with stakeholders and representative organisations of groups that may not be so vocal in issues of public health, but which may nonetheless represent important and vulnerable target groups.

### **7.4 Poor Levels of Control**

The involvement of private stakeholders can raise issues of accountability, given that they are not subject to the same control mechanisms as public sector organisations. Important issues include a failure to have defined clearly the roles for the many and varied stakeholders involved in a public health partnership (this was for example the case with the Global Polio Initiative and the Global Alliance to Eradicate Leprosy see (Mercer, 2002)). Complacency in the precise delegation of roles can create difficulties in monitoring the performance of the many and varying stakeholders that are involved. Without the ability to monitor stakeholder performance adequately it can be difficult to ensure accountability to the partnership as a whole. In order to minimise such problems the use of well defined ‘Memoranda of Understanding’ (MoU) has been suggested. The use MoUs could clearly identify the expected roles of any stakeholders in a communications plan and outline what benefits would accrue to them in order to allow them to carry out their agreed responsibilities. Such agreements would allow members of the public to exercise a certain level of accountability *vis-à-vis* the public authorities (e.g. national, European or International) that have opted to involve such stakeholders.

### 7.5 Hidden or Unknown Ideological Agendas

Further problems in terms of stakeholder selection can come through poor background research of private stakeholders (Buse, 2003).<sup>65</sup> In terms of the NFM such research may be important for example in terms of screening out potentially harmful commercial interests or groups that purport to speak on behalf of a community without any form of confirmed consensus on the part of the community in question. Failure to screen such partners properly could result in the selection of stakeholders that do not actually represent those who they claim to represent or stakeholders for whom trust issues may exist on part of the target audience. One possible example could be a religious group purporting to represent all members of a certain religion in a situation that might in fact be complex (with perhaps differing professions of the same faith e.g. Sunni and Shia Islam). Such a screening process might be improved for example with some level of direct consultation with target groups on the potential acceptability of proposed stakeholders.

A similar issue of accountability and screening relates to organisations with problematic ideological or theological agendas. Such an issue may occur where representative individuals or organisations therein have beliefs that may be incompatible with the neutral and open ethos that is taken to categorise most public health activities of the state. This might occur for example where a potential community organisation holds negative views concerning other sections in society. This could include views against religious majorities, and ethnic groups, sentiments of hatred or intolerance to certain behaviours and sexualities. The involvement of such stakeholders would run risks in terms exclusionary effects on individuals who may be the subject of such criticism. This threat may be particularly true for individuals that may *prima facie* be members of a minority represented by a stakeholder but may also openly or secretly have links to characteristics that the stakeholder in question may be known to vilify. This could for example be the case with individuals who might fall under the broad category of a religious minority but who may at the same time fall within another group (e.g. being homosexual) that may be the target of vilification by important members of the community in question (e.g. a religious minority). As TELL ME Deliverable 1.6

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<sup>65</sup>See for example Buse, K. (2003). *Governing partnership—A comparative analysis of the organizational and managerial arrangements of 18 global public–private health partnerships*. Geneva: Initiative for Public–private Partnerships for Health.

described, such a situation can risk the alienation and stigmatisation of affected individuals, something that can result in harmful consequences, including, inter alia, issues of treatment avoidance.

Such issues should also therefore be included in the screening process of potential stakeholders. Such a screening process would require a delicate balance to be drawn between the potential impact stakeholders can have in reaching important groups in society (e.g. ethnic, religious and racial minorities) and any potential they have for alienating or stigmatising other groups. Such an exercise will be difficult because the very nature of a pluralist society means that various groups in society are likely (and are permitted) to hold negative views about each other (Rawls, 2005).<sup>66</sup> What is important however is to recognise that no one group exists in a vacuum and that the views of each stakeholder in the context of a pandemic may affect the receptivity of individuals to public health messages not only in their receptive groups but also in the wider society. It will of course not be sensible to exclude critical groups and stakeholders because they may have some mildly intolerant, in particular where they represent the best option to disseminate messages to important and difficult to reach groups in society. One option is to clarify that to utilise prior agreements such a Memoranda of Understanding to clarify that such views, where they exist, should not be associated with the state in general, public bodies, or the aims of the public health campaign in question. In order to aid such efforts Memoranda of Understanding could, where possible, be made open to the public.

## **Section 7 – Summary Points**

- **The New framework model will likely engage a range on none state actors in roles in public health communication that have often been seen as the domain of the state.**
- **This will include various private stakeholders and community representatives.**
- **The lack of accountability (in comparison with public bodies) poses risks, including increased risks of negative outcomes for private individuals.**
- **Public health bodies will need to be attentive in order to ensure that a disproportionate level of involvement is not given solely to those private actors that have the means and resources to shout the loudest, at the expense of other actors that may be important but not so prominent.**
- **There exist risks that some private actors will pursue their own hidden agendas (e.g. commercial), and that their inclusion may offend certain groups of the population.**
- **Careful screening procedures should be employed to avoid these issues where possible.**
- **The use of well designed Memoranda of Understanding may be useful in clearly defining the roles of private stakeholders in an open and transparent way.**

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<sup>66</sup> The ideas here will be explored in greater detail in the section 8.1 in in the context of a discussion concerning self-respect.

## 8. Political Issues Associated with Stakeholder and Community Involvement in the NFM

The New Framework Model is innovative in its expectation that public sector bodies should utilise and work with a range of private stakeholders. Such stakeholders could range from large international private organisations to organisations that represent minorities in certain states (see deliverable 3.2).<sup>67</sup> The selection of, and the methods of working with such groups, are likely to have political implications because such co-operation will be perceived to amount to recognition and, to a certain extent, approval of the stakeholder in question. Such issues can raise sensitive issues because the recognition of various groups may entail the recognition factual situations (that may not be accepted by society as a whole), of various philosophical, political moral or religious beliefs. The recognition (even if only perceived) of one of these last categories may be contentious given the pluralistic nature of most democracies (Rawls, 2005).

### 8.1 The Perception of State Neutrality

#### *A Neutral State as an Independent Arbiter*

Most western democracies have a vision of the state as an institution that is primarily neutral in its opinions and judgements of its citizens (Madeley, & Enyedi, 2003). This is seen by the way that a state is expected to provide services and uphold the rights of all of its citizens, no matter what their beliefs or opinions (so long as they act within the law of course). Examples of such expectation can be found in the many and varied constitutional provisions that exist in various countries concerning the requirements on secularisation of the state and on various requirements of non-discrimination. Perhaps one of the most important advocates of such a neutral role for the state has been the American Legal philosopher *John Rawls*. In *Political Liberalism* (Rawls, 2005) he outlined his vision of modern society as not one homogenous society that share a broad moral, political and religious version of life (or *the good* as he terms it), but as being comprised of different groups of individuals, who are likely to hold a large variety of views on every subject, some of which are likely to be diametrically opposed to each other. The existence of such divergence in interests and views raises the spectre of conflict amongst various groups that, because of their views and interests in life, may desire a different arrangement of the society in which they live. Imagine for example a group in society that holds an absolute belief in God and another group that may profess to be atheist or agnostic. The first group might wish for society to be run entirely along religious lines (i.e. as a theocracy) where children are educated in school according to the views of the religion in question and where laws are only promulgated that reflect their interpretation of their sacred texts. The second group however may wish that society was run on a completely secular basis, with religion being forbidden in the class room and finding no part in the legal system. This question of how a society might be able to reconcile such difference in the best interests of all in society, interested Rawls. For him it demanded the existence of a liberal minded state (which exists in different flavours at the heart of most Western democracies) at its core that would be able to reconcile the various interests of the varying groups in society in a way that was respectful and beneficial to all.

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<sup>67</sup> For an analysis of the types of stakeholders that could be used under the NFM see TELL ME Deliverable 2.1 – Stakeholder Directory and Map

What Are the Requirements of the Liberal State

A Liberal State would clearly have to represent the interests of all of its citizens, even when they were divergent. A clear problem would however exist in deciding what such arrangements would entail given that the various groups present in any society would likely demand that the arrangements of any society would be skewed in their favour (Rawls 1993). In order to provide guidance on this issue Rawls created the concept of the *original position* and the *veil of ignorance*. At the centre of these concepts lies a thought experiment where the various individuals that comprise a society would be gathered and asked how a fair and just society should be run. Unlike normal individuals however, these hypothetical individuals would not know what beliefs they would hold in society, nor the position they might occupy in any hierarchy that might exist. Rawls reasoned that behind such a *veil of ignorance* individuals would have to reason objectively over what would constitute a fair society. Individuals would not for example know whether they would be religious or not, left wing or sectarian, male or female, a member of a majority group or of a despised minority. In such a position, where it was entirely possible that each and every person could become anyone of these, it would be illogical to demand a society where one was treated unfairly. Equally it would be illogical to demand a society where one of these possible types of people were prevented from obtaining the necessary goods needed in life (e.g. food shelter, basic income etc.), even to prosper to the most basic level. This original thought experiment allows one to reason about a number of requirements that must be present in a society for it to be fair and importantly in an objective and not a subjective manner.

Rawls reasoned that there would be several basic requirements that would be able to guide the organisation of society. The first would be a requirement that all citizens would be treated equally by the law. Such a requirement represents a requirement of non-discrimination before the law and can be observed in the constitutions of many societies (Courtwright, 2006). Another important requirement was the need for a society (and in particular the state) to foster what Rawls termed '*the social bases of self-respect*'. Self-respect for Rawls represents the ability to resist outside forces and opinions and to pursue one's own conception of the good life (Rawls, 1999:155). Possessing self-respect allows one therefore to live their life how they wish and pursue their version of the good, no matter how other members of society may feel about it. It may allow for instance a person to state that he is an atheist in a predominantly religious society or allow an individual openly admit they are homosexual in a society that contains homophobic elements. Without self-respect individuals would be unable to pursue their interests in life, even where they could obtain the material elements needed from so. This is because individuals would find it difficult to resist the negative opinions exerted by other members of society in processes such as stigmatization. The importance of self-respect to individuals in their societal life is therefore fundamental, and something which thinkers other than Rawls also appear to agree with (Nussbaum, 2003).

In *Political Liberalism* Rawls suggested that the state should promote individual self-respect by avoiding endorsing or shunning the various versions of the good life that exist in society. In doing so, states should avoid doing anything intended to favor or promote any particular concept of the good over another (Rawls, 1993). Failing to do so would send messages to individuals in society that certain concepts of the "good" were favored by society over others. This would have a steering influence on individuals in choosing their desired path in life and should therefore be avoided. Given that many of the activities envisaged by the NFM will be perceived as representing state expressions, it is important that efforts are made maintain the principle of state neutrality as much as possible, even where they are made by private stakeholders.

## 8.2 The Relevance of Self Respect and State Neutrality for the New Framework Model

Conceptions of the neutral state, including the particular vision espoused by Rawls place a big emphasis on the expression of the state and its ability to harm the individual feelings of self-respect (Quinn & De Hert 2014). The importance of the state in society as a result of its legal underpinnings, its superiority in terms of resources, and perhaps most importantly, the sense of moral authority it has been invested with through the democratic process, mean that the expressions of the state are extremely important. Expressions that suggest the state values a particular group can boost the self-respect of the group in question and strengthen their perceived position in society. Increased self-respect means that such groups are more likely to be able to resist the negative stigmatizing opinions of others in pursuing their own particular version of the good life. Where the state however expresses negative or stigmatizing sentiments concerning a particular group, the result can be a harm to the self-respect of individuals in affected groups. This can render it more difficult for the group in question to pursue their version of the good and achieve their goals in life.

A state can express negative sentiments towards groups in two main ways. The first is by not applying the law equally to all groups in society. As Rawls stated the an important source of self-respect for individuals and groups is to see that they are valued equally by the law as equal citizens and are not discriminated against dimply because of the group they belong to (Rawls 1973). The second is in direct acts of expression including during activities such as health campaigns. A state is able to directly express its disapproval of certain groups and their activities as not being conducive to public health in the context of public health campaigns (Guttman & Salmon, 2004, Link & Phelan, 2006)).<sup>68</sup> A state may also however harm the self-respect of certain groups by endorsing and cooperating with certain third parties. This could occur where such third parties have made stigmatizing remarks or called for the discrimination of other groups in society. In such cases the act of recognition by the state and cooperation with the third party runs the risk that the state may also be perceived as endorsing such views. Given the perceived moral authority the state is often perceived to have, there exists the risk that in such circumstances the stigmatizing views held by the third party may be given a new resonance through a perceived association with the state. In terms of the NFM this risk presents itself through the selection of, and cooperation with various stakeholders that might be involved in the communication process. Some examples of potential problems that might occur in this area are discussed in the coming pages.

## 8.3 Engagement of Minorities

Minorities form a consistent subject in the literature on vaccination communication. The need to engage with hard-to-reach minorities is for example often mentioned (e.g. Guttman & Salmon, 2004). Minorities for various reasons may be harder to reach than the general population. They may speak a different language (see 8.4 below), be driven underground (because they partake in activities that are considered criminal) or may be distrustful of official authorities. The hard-to-reach nature of such groups means that they can, be to a varying extent, be resistant to vaccination (Bryant, 2006). It is therefore logical to attempt to reach such groups through the engagement of stakeholders that may have closer ties and greater levels of trust with such groups.<sup>69</sup>

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<sup>68</sup> Many examples of this were discussed in TELL ME Deliverable 1.6

<sup>69</sup> This is also something that the WHO demands Work -Checklist and Indicators for Monitoring Progress in the Development of IHR Core Capacities in States Parties April 2013 WHO/HSE/GCR/2013.2



### The Act of Recognition

The process of selection and engagement of minority stakeholders may however be associated with problems. In some countries, the legal situation makes it difficult to assess how many members of various minority groups there are and where they live. This may be because of anti-discrimination philosophies that aim to treat all citizens the same through showing a degree of blindness to difference in terms of ethnicity or origin (e.g. in France). In such instances the recognition of minorities in terms of a special stakeholder for public health communication may run into certain problems. The *de facto* recognition of certain minority groups may for instance be ill perceived by non-minority citizens who may feel resentment to what they perceive is a form of special treatment. This may create stigmatising or discriminatory attitudes in such individuals which could result in negative consequences for the individuals concerned. In addition, some members of minorities may themselves resent being tagged as members of a minority (May et al. 2004). Doing so may make some individuals feel that they are not viewed as ordinary citizens, but as a special category deserving extra (perhaps viewed as negative attention). Individuals within minorities may well react differently to each other on being targeted and identified. Imagine for example the large and complex 'Arab minority' in many European states. Some individuals in this over simplified classification may represent 2<sup>nd</sup> or even 3<sup>rd</sup> generation citizens that have become fully integrated into the societies in which they live. They may, as a consequence, view themselves as French of Arab descent, but not as a 'Arab'. Others however may be more recent arrivals, may not yet have wanted to (or been able to) integrate well and may not speak the local language so well. Such individuals may feel more comfortable with the tag of being a member of a minority and the special attention it brings with it.<sup>70</sup>

Other problems may occur because individuals may not be legally registered where they live or may even be illegal immigrants. Factors such as these can make difficult the forming of an accurate picture of the make-up of ethnic minorities in a country. Given this, it may be difficult to determine which minorities to work with and for which stakeholders to opt for. In such a situation there exists the possibility that resources will be directed to groups that are disproportionately vocal or groups that are deemed more politically acceptable than others. For those minorities that for one reason or another are marginalised, there also exists the reason that an oversight may be taken as an expression as a lack of respect or acceptance and further strengthen sentiments of stigmatisation of estrangement that they might feel.

### (ii) Choosing Representatives

A further issue may involve the selection of the actual stakeholder best perceived to connect with a certain minority. Such partners in communication can bring added value because they bring with them better knowledge of their respective community and how to communicate with it (Buse & Harmer, 2007). This is because centralised public health agencies may not be able to understand the various minorities, and the dynamic groups that make up a society. The problem is that such a knowledge gap may also make it difficult to discern which stakeholders most accurately represent various minority groups and which are best able to communicate with them. Some purported community organisation may not be acceptable to some sections of the community. This may for example be the case where the organisation in question holds views that are considered too conservative or progressive for some minority members (Guttman &

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<sup>70</sup> In addition it is important to remember that the 'Arab community' is composed of groups with diverse social origins and diverse cultural influences. Imagine for instance the difference between individuals with Moroccan origins and those with Syrian origins.



Salmon, 2004). Other problems may occur through a simplistic understanding of the minority in question. In such situations public health planners might not appreciate complexity within minorities. These might exist in relation to intra-group tensions linked for example to difference in geographical origin or perhaps difference in religious belief that not may be fully appreciated by non-minority members. This could be for instance the case where for example the Muslim minority is labelled as one coherent minority when in fact there are several different strands of Islam present in most European countries, and also significant cultural variations linked to each group's country of origin.

The above represents only a small range of possible areas where lack of knowledge and understanding may result in negative effects. The lack of legal enforcements associated with good governance practice (discussed above in section 3) may increase the risk, given that there will be limited legal requirement to seek input from effected parties (see section 3). It is however essential for public health bodies involved in stakeholder selection to make efforts to address such issues. Doing so will likely involve making sure that adequate possibilities are given for affective minorities to be informed of and, where necessary, to challenge the selection of a potential stakeholder representative that may pertain to them. This can occur in the planning phases prior to an actual pandemic. Being open to such consultation will allow individuals to make effective representation about aspect that may concern them, including the choice of a particular stakeholder and how it may communicate with the minority in question. Having such a possibility before a pandemic occurs will avoid sensitive issues occurring in the midst of a pandemic and the potential negative issues that may be associated with unnecessary stigmatisation such as treatment avoidance (Kreuter & McClure, 2004).<sup>71</sup> In addition, it will be important in the post pandemic phase to learn lessons in terms of stakeholder selection. This will include instances where perceived community representatives have cause more harm than good.

#### 8.4 Recognition of Languages

Whilst for many individuals involved in public health communication language may be a practical issue that can be overcome with adequate translation, for many societies the subject of language can form a sensitive political issue (Joseph, 2006). In some societies the issue of language may be tied to a minority status, for example with immigrants. That a different language is spoken in an immigrant community may go some way to defining what differentiates them from the majority in society. In such cases language will be intricately tied to many of the issues discussed above for the selection of stakeholders that are able to communicate effectively with minority groups. In such cases most of the issues discussed above would also apply to the involvement of minority immigrant languages in public health communication programmes.

Most modern societies have histories of immigration and therefore a diversity of minority languages that are only significant in that they are the languages spoken by a minority immigrant community. In some societies the issue of language may be much more sensitive. This can happen for example where various different groups, each speaking different languages have historically cohabited a region that is now a modern state. In such instances the issue of language may often be connected to issues of cultural rights and even the sovereignty of the state. Belgium can be used as an illustrative example for many states given its history of language based politics. In that country there exist Dutch, French and German speaking communities (Joseph, 2006). Whilst all individuals may have the same Belgian citizenship

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<sup>71</sup> Examples of such phenomena were discussed in deliverable D1.6 in particular associated with the H1N1 (the Mexican community) and the SARS (the Chinese community) outbreaks

the official recognition of language may change from one part of the country to the other. In Brussels for example, French and Dutch are official languages whereas in Flanders and Wallonia only one official language is recognised, (i.e. Dutch and French respectively). Laws often restrict official communications to the official language in that region. The use of the French language in Flanders, has in recent decades, proved to be a sensitive issue. Despite a having a French speaking minority (who often may not understand Dutch) the Flemish region has resisted (including through legal actions) as much as possible the use of the French language in interactions between the state and its citizens.<sup>72</sup> In other states historical minorities may have always existed, but their language may never have gained political recognition. This may for example be the case with many Roma people that live in central and Eastern Europe that do not speak the local language as mother language (Hemetek, 2006). In the Baltic states, Russian is spoken by a large minority and the use of Russian by the state is an extremely sensitive issue (Adrey, 2005).

The selection of language will often be important in such situations because the choice of language may, to a certain extent, indicate ownership of the terrain in question, suggesting that one culture or another is at home in such a situation. In Dutch speaking Belgium for example there has been a long historic fear of '*verfransing*' – a term that represents a process by which the French language and culture were gradually taking over once Dutch speaking areas. Similar issues exist in the Baltic states. Often such a fear will be created where encroachment is feared from a neighbouring language or culture that is much larger i.e. French in Belgium and Russian in the Baltic States. As a result of this the use of the other threatening language by the state may be politically unacceptable, representing a sign of submission to another's culture. As a result of such historical, cultural and political concerns it may be one particular language in a particular area that is sensitive.<sup>73</sup>

Given the political sensitivity of language choice in some contexts it will be necessary to have a communication strategy that is sensitive and adaptable to such contexts. The utilisation of community representatives as stakeholders in the communication process (as envisaged in the NFM), may present an opportunity to deal with some of these issues in a sensitive manner. This is because such organisations will often be private in nature and will not thus constitute a component of the state. This is important because the highest level of sensitivity in both a political and legal sense usually relates to the language used by the state and public bodies in their communications.<sup>74</sup> Through using private community representative organisations as proxies it may be possible to avoid such issues. This is because the state (i.e. through public health bodies) can provide information needed to communicate on public health issues in a legally and politically acceptable manner. The community organisation can then disseminate such information to members of its respective community in the required language. The use of a language that is politically sensitive will likely raise less issues when it is used by a party that is perceived of as being private and not representing an official part of the state. In addition, the rise of the internet and various forms of social media, in concert with the growth in the use of smartphone devices means that old conceptualisations of information campaigns are no longer valid. The central focus of a modern campaign is not likely to be the use of flyers, leaflets and posters etc., that may be visible for all of society to see but through the use of more targeted efforts focused on the use of social media or more targeted messaging (perhaps through

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<sup>72</sup> The Brussels Capital Region is surrounded on all sides by the Region of Flanders. As a consequence many French speaking people have migrated the short distance to live in Flanders, but have often stayed connected to the use of French despite it not being the official language there.

<sup>73</sup> In most of the examples above English may for example be used frequently in many circles without creating such issues. This is because although English may be a language with ever increasing contemporary dominance and recognition on the world scale, it will not have the historical and cultural relevance that languages of the type discussed here will.

<sup>74</sup> There may for example often be legal provisions restraining the state in terms of the use of languages it may use in official communications.

email or messaging services like ‘Whatsapp’ or ‘Twitter’). Given that the latter type of communications is much less conspicuous than the former, it will likely raise fewer issues connected to the sensitivity of language choice. Indeed, with the latter type of methods, other sensitive members of society need not even be aware of most of the communication that is taking place if they do not want to be.

### 8.5 Recognition Of, and Working With religious groups

The choice of religious stakeholders, like those connected to language and minority status (e.g. immigrant communities), will be sensitive in terms of its expressive component. In terms of expressive value, issues of religion can, in many circumstances, be even more controversial than these other issues. This is because the issue of religion (or the choice not to have one) is arguably to a greater extent connected to ideas of morality, philosophy and spirituality than an immigrant’s origin or their choice of language. An individual’s religion may inform an individual on how their personal life should be lived and how society should be organised. Whilst such opinions may be acceptable to a particular religious community, they may be offensive to other groups in society (Modood, 2010). This may especially occur when beliefs or lifestyles conflict with the beliefs of the religious group in question. In such instances members of the religious group in question may be known to criticise other groups that do not live in a way that fits with their religious beliefs (Severson et al., 2014). Perhaps the most common example of this involves those with conservative religious views who criticise those who engage in sexual practices or form family structures that are considered immoral by religious groups. This may occur with single parent families, unmarried couples living together or homosexual couples for example. Such criticism can be offensive to affected groups. In addition, it can be stigmatising and threaten individual self-respect. Imagine for instance a member of the latter group that lives in an area of a city that is predominantly populated by members of a certain religious group that holds conservative views on such issues. Frequent exposure to such stigmatising opinions may change the behaviour of the individuals in questions, altering what they say, where they go and to whom they are open to (Link & Phelan 2001).

In modern liberal societies however (as discussed above) individuals are provided protection in both a physical sense and also a philosophical and moral sense by a liberal state (see section xx above). The latter, as was discussed above is achieved by valuing all citizens equally, irrespective of their views of what constitute ‘the good’ (Rawls, 1973). In showing equal respect to all citizens<sup>75</sup>, the state shows that it values them ‘first and foremost’ as a citizen of equal value to all other citizens. The existence of the liberal non-judgemental state in doing so is able to provide a valuable source of reassurance to all of its citizens that they are of equal moral value to all others in society. As Rawls suggested such reassurance can be important in strengthening individual self-respect in a world where we may be faced with critical and stigmatising voices of disapproval daily. In order to maintain such a neutral, non-judgmental standing towards all of its citizens it is important for the state not to demonstrate disrespect towards certain groups or to associate itself with groups that express negative and stigmatising sentiments to certain other groups of citizens. This is why it is important for public bodies to be careful whom they associate themselves with, including in the context of public health campaigns. Association with certain groups or organisations might give the impression that the state shares such views. In such instance this runs the risk not only that the state loses its image of neutrality and equal respect (potentially harming the self-respect of individuals as

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<sup>75</sup> As was discussed in section 8.1 above Rawls reasoned that a state could show equal respect to its citizens by treating them equally in the law and through doing nothing to harm their bases of self-respect e.g. through experiencing disdain for a particular group.

Rawls would argue) but also that it might give a platform to such stigmatising views giving them increased potency etc. Imagine for instance a public health agency that publicly associated itself with a religious organisation that openly espoused homophobic views or views that were against other religions. In doing so such public organisations might risk their position of being viewed as neutral and respectful of all lawful groups in society and may even risk being seen as sympathetic to the stigmatising views of a certain section in society. An important risk in such a situation is adherents of a particular religion might feel more pressurized to follow the views of their community leaders, even when they are not what they might otherwise wish to do, or even where they may be in contradiction with medical advice.

Bringing such developments about, in the context of a public health campaign such as that envisaged in the NFM, would be counter-productive and ethically dubious for two reasons. First it might reduce the trust that certain minorities have of the state, its public health bodies and the messages they wish to disseminate. Second, it could worsen already problematic situations of stigmatisation for individuals have been the subject of attacks by other groups in society. Both of these issues are associated *inter alia* with issues of healthcare avoidance amongst stigmatised minorities (Link and Phelan 2006). It will thus be important for public health bodies to be sensitive to such issues when selecting stakeholders to aid with communication with various religious groups. As suggested in section 7 it will be important to bear this in mind in the screening stage of selecting potential stakeholders. This will likely involve a careful analysis of the history of each organisation in particular for any contentious views it might possess. Such concerns will have to be weighed against the need to communicate with individuals from the societal group in question in the context of a pandemic and the added value that the potential stakeholder can bring, especially in communicating concerns in areas that might be culturally sensitive (Wong, 2008). Whilst it would accordingly be unrealistic to expect all stakeholders to have unblemished records of complete tolerance, it would however be advisable to avoid potential stakeholders that have histories of connections with extremism or voicing hateful opinions against others in society. Another approach could involve the equal engagement of potential stakeholder representatives from all groups in society. This is because public bodies would be showing neutrality and equal respect through engagement with the various groups in society, even where they may hold disrespectful or hostile views about each other. In addition, the use of various agreements or Memoranda of Understanding could be used to underline the fact that the state or any other public entities do not share the views of one stakeholder or strand of society concerning other groups.

## Section 8 – Summary Points

- **The attitudes and expressions of the state are important in demonstrating that it is neutral in regards to the various and many groups that exist in modern pluralist societies.**
- **Maintaining such neutrality is important in demonstrating that all individuals are viewed as equal citizens.**
- **The engagement of various private groups by the state may also be seen as endorsing some of these groups.**
- **This could create problems where the group in question has hostile views towards others in society (e.g. intolerant of certain behaviors or minorities).**
- **There are also risks associated with using various minority languages. This includes the risk of stigmatization for individuals that speak the language in question. In some societies the use of certain languages may be politically sensitive.**

- **The selection of stakeholders and community representatives will have to be conducted in a careful manner that is sensitive to these issues.**

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