Ethics assessment in different fields

Public health ethics

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Annex 2.c.5
Ethical Assessment of Research and Innovation: A Comparative Analysis of Practices and Institutions in the EU and selected other countries
Deliverable 1.1

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Contents

1 INTRODUCTION

1.1 PUBLIC HEALTH

Public health has long been recognised as having an essential role in human health.[1] Public health interventions date back over three centuries.[2] At the beginning of the 18th century, Massachusetts passed laws for the isolation of smallpox patients and quarantine of patients.[3] In the early 1800s in England, Edward Chadwick demonstrated that differences in social conditions led to a more than two-fold difference in life expectancy between upper and lower classes.[4] By the end of the 19th century, state and local boards of health were being established in order to enforce sanitary regulations and by the early 20th century, public health was viewed as both cost-effective and useful.[5] Historically, many of the most substantial advances in improving public health were made through non-medical developments such as clean air legislation, improved housing and sanitation, and workplace health and safety regulations.[6]

Public health is primarily concerned with the health of entire populations, as opposed to the health of individuals. The features of public health include an emphasis on the promotion of health and the prevention of disease and disability, the collection and use of epidemiological data, population surveillance and other forms of empirical quantitative assessment; a recognition of the multidimensional nature of the determinants of health; and a focus on the complex interactions of many factors – biological, behavioural, social, and environmental – in developing effective interventions.[7]

Public health can be distinguished from clinical medicine in a number of ways. Clinical medicine focuses on the treatment and cure of individual patients, while public health aims to understand and ameliorate the causes of disease and disability in a population.[8] Moreover, the physician-patient relationship is at the centre of medicine while concern for the health of a population involves "interactions and relationships among many professionals and members of the community as well as agencies of government in the development, implementation, and assessment of interventions."[9] Even though clinical medicine and public health both attend to justice, there is significant disparity in how they do so. The focus of justice in clinical medicine is usually faint and concerns distributive justice or ensuring that there is enough for

[1] Kenny, Nuala P., Ryan M. Melnychuk and Yukiko Asada, "The Promise of Public Health", *Revue Canadienne de Sante Publique*, Vol. 97, No. 5, September- October 2006, pp. 402-404 [p. 402].
[2] Kass, Nancy, E. "An Ethics Framework for Public Health", *American Journal of Public Health*, Vol. 91, No. 11, November 2001, pp. 1776-1782 [p. 1776].
[3] Ibid., p. 1776.
[4] Ibid., p. 1776.
[5] Ibid., p. 1776.
[6] Nuffield Council on Bioethics. "Public health: ethical issues", Nuffield Council on Bioethics, London, 2007, [p. 3]
[7] Childress, James F., Ruth R. Fadden, Ruth D. Gaare, Lawrence O. Gostin, Jeffrey Kahn, Richard J. Bonnie, Nancy E. Kass, Anna C. Mastroianni, Jonathan D. Moreno and Phillip Nieburg, "Public Health Ethics: Mapping the Terrain", *Journal of Law, Medicine & Ethics*, Vol. 30, 2002, pp. 169-177 [p. 169]. http://www.virginia.edu/ipe/docs/Childress_article.pdf
[8] Ibid., p. 169
[9] Ibid., p. 169.

everyone entitled to care.[10] The focus on justice in public health practice, on the other hand, emphasises social justice or rights to health care and disparities in access and outcomes.[11]
Several different definitions of public health exist, including that of the Institute of Medicine, which defines public health as "what we, as a society, collectively do to assure the conditions for people to be healthy".[12] The IOM's definition emphasises co-operative and mutually shared obligation ("we, as a society") and reinforces the responsibility of collective entities (governments and communities) for health populations.[13] Collective interventions in the service of public health often require government action.[14] For example, in the United States, the Centers for Disease Control and Prevention, the Food and Drug Administration and the Environmental Protection Agency are in part or in whole public health agencies. The activities of the World Health Organization serve to promote and protect public health at the global level.

Today, public health is more important than ever, as society faces the threats of emerging and resurgent infectious diseases (such as SARS), drug resistant forms of disease (such as tuberculosis) and the threat of bioterrorism.[15] In addition, the population faces the burden of non-communicable chronic diseases such as cancers, cardiovascular diseases, diabetes and respiratory diseases which are exacerbated by certain behaviours such as smoking, lack of physical activity and overeating.[16]

1.2 PUBLIC HEALTH ETHICS

Public health practitioners make decisions that have ethical implications, knowingly or otherwise.[17] If more funding is allocated to services for disadvantaged communities or a take-away is shut down due to a high incidence of food poisoning, public health practitioners are making choices that have ethical consequences and are most likely acting because they think it is "the right thing to do" or "just common sense".[18] Each of these actions can be linked to a well-established set of moral ideas; respectively, the importance of distributive justice or fairness and a belief that public health practitioners have a right to limit someone's freedom if they are doing harm to others.[19] While these ideas are deeply embedded in the social and professional culture of public health, they are rarely made explicit.[20]

Since the late 1990s, there has been an explicit focus on ethical issues in public health.[21] The nascent field of public health ethics borrowed heavily from the ethical tools developed for

[10] Lee, Lisa M., "Public health ethics theory: review and path to convergence", *The Journal of Law, Medicine and Ethics*, Vol. 40, No.1, 2012, pp. 86-98 [p. 87].
[11] Ibid., p. 87.
[12] Committee for the Study of the Future of Public Health, Division of Health Care Services, Institute of Medicine, "The Future of Public Health", National Academy Press, Washington D.C., 1988. http://www.nap.edu/openbook.php?record_id=1091
[13] Gostin, Lawrence P., "Public Health", in Mary Crowley (ed.), *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns,* The Hastings Center, Garrison, NY, 2008, pp. 143-146 [p. 143].
[14] Stanford Encyclopaedia, Public Health Ethics, 2010, http://plato.stanford.edu/entries/publichealth-ethics/
[15] Gostin, op. cit., 2008, p. 143.
[16] Ibid.
[17] Carter, Stacy M., Kerridge, I., Sainsbury, Peter and Julie K. Letts, "Public health ethics: informing better public health practice", *NSW Public Health Bulletin*, Vol. 23, No. 5-6, 2012, pp. 102-107 [p. 101].
[18] Ibid., p. 101.
[19] Ibid., p. 101.
[20] Ibid., p. 101.
[21] Lee, op. cit., 2012, p. 86.

research ethics and bioethics; however, it quickly became evident that the clinical model could not be readily applied to public health issues.[22] In 2001, in "An Ethics Framework for Public Health", Nancy Kass suggested that "the contexts out of which bioethics emerged – medical care and human research – were oriented toward a different set of concerns than those typically arising in public health".[23] Specifically, "Codes of medical and research ethics generally give high priority to individual autonomy, a priority that cannot be assumed to be appropriate for public health practice".[24] Similarly, in 2002, Callahan and Jennings observed that "In early bioethics, the good of the individual, and particularly his or her autonomy, was the dominant theme, not population health".[25] The same authors went on to identify one major obstacle in bringing public health and bioethics together, namely "the difference between the individualistic orientation of bioethics and the population and societal focus of public health."[26]

The features differentiating clinical and public health practice (see section 1.1) lead to different ethical challenges and presumptions in the respective fields.[27] As Lee notes, "The moral governance needed for public health did not translate directly from the principles of bioethics, as transmuted for research ethics in the 1940s and 1950s or clinical ethics in the 1960s and 1970s."[28] A series of controversies implicating the concepts of privacy, liberty and paternalism further underlined the incongruence between bioethics and public health ethics. [29] For example, surveillance – a critical element in the practice of public health – represents a "striking example of the ways in which the claim of public could intrude upon the privacy of the clinical relationship".[30] The early HIV/AIDS epidemic illustrated the inadequacy of clinical ethics to address urgent ethical challenges that straddled both public and private life.[31]

This inadequacy spawned pioneering work by theorists such as Ruth Kaden and Nancy Kass[32] and Lawrence Gostin and William Curran[33] to discuss ways to expand bioethics in the 1980s to include public health ethical concerns.[34] In 1988, Dan Beauchamp brought together health, equity, political philosophy and democratic theory to root public health ethics as a balance of, rather than a struggle between, individual freedom and community well-being.[35] Scholars and public health practitioners began to propose a variety of specific suggestions for ethical frameworks for public health in the 1990s.[36]

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[22] Ibid., p. 86.
[23] Kass, op. cit., 2001, p. 1776.
[24] Ibid., p. 1776.
[25] Callahan, Daniel, and Bruce Jennings, "Ethics and Public Health: Forging a Strong Relationship", *American Journal of Public Health*, Vol. 92, No. 2, February 2002, pp. 169-176 [p. 169].
[26] Ibid., p. 170.
[27] Ibid.
[28] Lee, op. cit., 2012, p. 87.
[29] Bayer, Ronald, and Amy L. Fairchild, "The genesis of public health ethics", *Bioethics*, Vol. 18, No. 6, 2004, pp. 473-492.
[30] Ibid, p. 480.
[31] Lee, op. cit., 2012, p. 87.
[32] Faden, R.R., and N. E. Kass, "Bioethics and Public Health in the 1980s: Resource Allocation and AIDS", *Annual Review of Public Health*, Vol. 12, May 1991, pp. 335-360.
http://www.annualreviews.org/doi/abs/10.1146/annurev.pu.12.050191.002003
[33] Gostin, Larry, and William J. Curran, "AIDs Screening, Confidentiality, and the Duty to Warn", *American Journal of Public Health*, Vol. 77, No. 3, 1987, pp. 362-365.
[34] Lee, op. cit., 2012, p. 87.
[35] Ibid., p. 87
[36] Ibid., p.87

2 VALUES AND PRINCIPLES

There does not appear to be a definitive set of values and principles in the public health ethics literature. Given broad conceptions of the field and varying views on the goals of public health, different approaches and theories for public health ethics have been developed since the beginning of this millennium.[37] In this section, we focus on some of the most well- known ethical frameworks created in this field. In addition, we focus in on those values which are widely accepted as inherent to an ethical approach to public health.

2.1 ETHICAL FRAMEWORKS

Nancy Kass of Johns Hopkins University wrote one of the earliest proposed ethical frameworks for public health.[38] In her article, Kass discussed the inadequacy of ethics codes for clinical practice for professional moral direction in public health and proposed a public health ethics code based on the preservation of the rights – both positive and negative – of the citizen, in addition to social justice considerations. Kass described several principles underpinning what she termed a "code of restraint" balanced by the "affirmative obligations to improve the public's health and, arguably, to reduce certain social inequities".[39] The key principles in the framework include the following: ensuring the minimal level of interference to improve population health in order to preserve the negative rights of citizens, identifying and minimising harms and burdens to the maximum extent possible while not greatly reducing programme effectiveness, reducing social inequities and health disparities, and providing evidence of programme benefits.[40]

In 2002, James Childress et al. endeavoured to offer a rough conceptual map of the terrain of public health ethics.[41] For these authors, the "relevant general moral considerations" include the following: producing benefits; avoiding, preventing and removing harms; producing the maximal balance of benefits over harms and other costs (often called utility); distributing benefits and burdens fairly (distributive justice) and ensuring public participation; respecting autonomous choices and actions; protecting privacy and confidentiality; keeping promises and commitments; disclosing information honestly and truthfully; and building and maintaining trust.[42] The authors consider these values to be prima facie. Furthermore, they propose five "justificatory conditions" – effectiveness, proportionality, necessity, least infringement and public justification – intended to help determine whether promoting public health warrants overriding such values as individual liberty or justice in particular cases.[43]

In the same year, Upshur distilled a set of principles for public health from a reading of the literature in public health ethics.[44] The focus of these principles relates to the question as to when public health action is justified. Moreover, these principles seek to elucidate some of the ethical aspects of public health decision-making in practice. The four principles include the harm principle, the principle of least restrictive or coercive means, the reciprocity principle and the transparency principle. The harm principle, as set out by John Stuart Mills, was

[37] Ibid., p. 88.
[38] Kass, op. cit., 2001.
[39] Lee, op. cit., 2012, p. 96.
[40] Ibid.
[41] Childress et al., op. cit., 2002, pp. 169-177.
[42] Ibid., pp. 170,171.
[43] Ibid., p. 172.
[44] Upshur, R.E.G., "Principles for the Justification of Public Health Intervention", *Canadian Journal of Public Health*, March - April 2002, pp. 101-103.

described by Upshur as the foundational principle for public health ethics, as it is the initial justification for a government or government agency to take action to constrain the liberty of an individual or group. The least restrictive or coercive means dictates that, while a variety of means are available in order to achieve public health ends, the least restrictive means should be employed unless circumstances necessitate more coercive methods. The reciprocity principle holds that society is obliged to facilitate individuals and communities to discharge their public health duties. The transparency principle requires stakeholder involvement in the decision-making process, with equal input into deliberations and a clear and accountable decision-making process. Upshur concludes by calling for evaluation of utility of these principles in practice.

A few years later, following the global SARS (Severe Acute Respiratory Syndrome) epidemic and while preparing for pandemic influenza, Upshur worked with colleagues in Toronto to further develop his ethical framework.[45] Alison Thompson et al.[46] presented an applied ethical framework for pandemic influenza planning developed with expertise from clinical, organisational and public health ethics and validated through a stakeholder engagement process. The first part of the framework identifies five key elements of ethical decision-making processes and includes the following:

- accountability: requires that mechanisms are in place to ensure sustained ethical decision-making throughout a crisis
- inclusiveness: requires that decisions should be made explicitly with stakeholder views in mind
- openness and transparency: this value holds that decisions should be publicly defensible, with a communication plan developed in advance to ensure that information is readily available to affected stakeholders
- reasonableness: decisions should be based on reasons (i.e., evidence, principles, values) that stakeholders can agree are relevant to meeting health needs
- responsiveness: this value holds that opportunities should be available to revisit and revise decisions as new information becomes available, in addition to the need to have mechanisms to address disputes and complaints

The second part of the framework identifies 10 key ethical values that should inform the pandemic influenza process and decision-making during an outbreak. The 10 ethical values include the following:

- duty to provide care: sets out health care professionals' inherent duty to provide care and to respond to suffering
- equity: which ensures that, all things being equal, all patients have an equal claim to receive required health care
- individual liberty: which requires respect for personal autonomy, employing the least restrictive means to achieve public health goals
- privacy: which underlines the importance of individuals' right to privacy in health care by allowing the disclosure of private information that is relevant to achieve legitimate and necessary public health goals and only if there are no less intrusive means to protect public health

[45] Lee, op. cit., 2012, p. 88.
[46] Thompson, Alison, K., Karen Faith, Jennifer L. Gibson and Ross E.G. Upshur, "Pandemic influenza preparedness: an ethical framework to guide decision-making", *BMC Medical Ethics*, Vol. 7, No. 12, 2006.

- proportionality: which requires that restrictions to individual liberty should not exceed what is necessary to address the level of risk or the need of the community
- protection of the public from harm: the obligation to protect the public from serious harm is a foundational principle of public health ethics
- reciprocity: requires that society supports those who face a disproportionate burden in protecting the public good (i.e., health care workers, quarantined individuals or families of ill patients) and takes steps to minimise their impact as far as possible
- solidarity: emphasises the need for solidarity across systemic and institutional boundaries in stemming a serious contagious disease
- stewardship: requires those entrusted with governance of scarce resources (e.g., vaccines, ventilators, hospital beds) to be guided by the notion of stewardship embodying trust, ethical behaviour and good decision-making.
- trust: trust is an essential component throughout the health system and takes time to build with various stakeholders.

We turn now to discussion of other widely accepted values in public health ethics.

2.2 FUNDAMENTAL VALUES IN PUBLIC HEALTH ETHICS

Paternalism

An important empirical, conceptual and normative issue in public health ethics is the relationship between protecting and promoting the health of individuals and protecting and promoting public health.[47] A focus on population-based health "requires a population-based analysis and a willingness to recognise that the ethics of collective health may require far more extensive limitations on privacy, as in the case of public health surveillance, and on liberty, as in the case of isolation and quarantine, than would be justified from the perspective of the autonomy-focused orientation of the dominant current in bioethics".[48]

The associated ethical question is "when can paternalistic interventions (defined as interventions designed to protect or benefit individuals themselves against their express wishes) be ethically justified if they infringe general moral considerations such as respect for autonomy, including liberty of actions?"[49] The case against paternalism assumes that individuals are interested and are the most informed about their own needs and value systems.[50] The case for paternalism usually relies on internal and external constraints on people's capacity to pursue their own interests, with the implication that state regulation is sometimes necessary in order to protect an individual's health or safety.[51]

Social justice

Social justice has been described as the core value of public health. Among the most basic and commonly understood meanings of justice is fair, equitable and appropriate treatment in light of what is due or owed to individuals or groups.[52] Thus, justice, for example, can offer

[47] Childress et al., op. cit., 2002, p. 174.
[48] Bayer and Fairchild, op. cit., 2004, p. 491.
[49] Ibid.
[50] Gostin, op. cit., 2008, p. 145.
[51] Ibid.
[52] Gostin, op. cit., 2008, p.145.

guidance on how to allocate scarce resources in a public health crisis.[53] Social justice also calls for policies of action that preserve human dignity and show equal respect for the interests of all members of the community.[54]

Human rights

There is broad agreement that a commitment to improving the health of those who are systematically disadvantaged is as constitutive of public health as is the commitment to promote health generally.[55] In this regard, there is an intimate connection between public health and the field of health and human rights.[56] The field of health and human rights is ubiquitous and official: it is recognised in international treaties such as in Article 12 of the International Covenant on Economic, Social and Cultural Rights and its practitioners are found in UN agencies and in much of the world.[57] Most notably, Jonathan Mann, an American physician working for the World Health Organization, noted that the fields of public health ethics and human rights have "seeped into the other, making allies of public health and human rights, pressing the need for an ethics of public health, and revealing the rights-related responsibilities of physicians and other health care workers".[58] Indeed, both fields address many of the same issues, include health care priority-setting, the ethics of research with human subjects, ethical limits on public health interventions that threaten civil liberties and public participation in health policy.[59]

2.3 THE EUROPEAN CONTEXT

In 2007, the European Commission issued the White Paper "Together for Health: A Strategic Approach for the EU 2008-2013" (hereinafter the 'Health Strategy) [60], the aims of which were to set out a new Community health strategy 1) designed to confront the growing challenges to the health of Europe's citizens and 2) to strengthen Community cooperation in a single strategic framework, to ensure that health is better understood at European level and worldwide, and to secure a greater role for health in all policies. To that end, the White Paper proposes four principles and three strategic objectives.

The Health Strategy (HS) sets its foundation on the overarching values of universality, access to good quality care, equity and solidarity. These values derive from the Council Conclusions on Common Values and Principles in European Union Health Systems (hereinafter the 'CC')[61] and are given a central position by the Commission in the HS.

Universality "means that no-one is barred access to health care". Solidarity "is closely linked to the financial arrangement of our national health systems and the need to ensure accessibility to all." Equity relates to "equal access according to need, regardless of ethnicity,

[53] Ibid., p. 145.
[54] Gostin, op. cit., 2008, p.145.
[55] Stanford Encyclopaedia of Philosophy, "Public Health Ethics", 2010. http://plato.stanford.edu/entries/publichealth-ethics/
[56] Ibid.
[57] Wickler, Daniel, and Dan W. Brock, "Population-level bioethics: Mapping a new agenda", in Angus Dawson and Marcel Verweij (eds.), *Ethics, Prevention and Public Health*, Oxford University Press, New York, 2007, pp. 78-94 [p. 82].
[58] Mann, Jonathan M., "Medicine and Public Health, Ethics and Human Rights", *Hastings Center Report*, Vol. 27, No. 3, May-June 1997, pp. 6-13 [p. 6].
[59] Wickler and Brock, op. cit., 2007, p. 82.
[60] http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf
[61] http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2006:146:0001:0003:EN:PDF

gender, age, social status or ability to pay. EU health systems also aim to reduce the gap in health inequalities, which is a concern of EU Member States; closely linked to this is the work in the Member States systems on the prevention of illness and disease by, inter alia, through promotion of health lifestyles". In addition, health systems "should be patient-centred and responsive to individual need". The document goes on to state that the HS will also take forward the gender dimension which derives from the Council's Conclusion on Women's Health.[62] The HS also refers to the Charter of Fundamental Human Rights[63] which recognises citizens' rights of access to preventive healthcare and the right to benefit from medical treatment. Citizens' empowerment is another core value of the HS. Citizens' and patients' rights are taken as a key entrance point with participation in and influence on decision-making in addition to competences needed for health well-being such as "health literacy" emphasised. Reducing inequities in health is another value of the HS with proposed actions aimed at reducing health inequities including targeted health promotion and best practice health exchange. Finally, health policy "must be based on the best scientific evidence derived from sound data and information and relevant research".[64]

Schröder-Bäck et al.[65] offer an ethical analysis of the scope of the HS. The authors observe that equity is used in order to promote justice and the other three overarching values can be understood as specifications of equity and of social justice. In addition, the HS has a rights-based orientation determined on a level of basic values. The authors observe that "a genuine consequentialist public health ethics values that would add another ethical tradition and complementary schools of thought (such as *do no harm*, or *health maximisation*) are missing."[66]

In its multi-annual programme of action for health (2014-2020), the European Commission presents its programme covering the period 2014-2020.[67] The Health for Growth Programme (2014-2020) helps/supports Member States in order to:

- Undertake the necessary reform to achieve innovative and sustainable health systems
- Improve access to better and safer health care for citizens
- Promote good health of European citizens and prevent diseases
- Protect European citizens from cross-border threats

3 ETHICAL ISSUES

In order to outline ethical issues in the field of public health, it is necessary to distinguish the core functions of public health, which include health protection, health surveillance, disease and injury prevention, population health assessment, health promotion and disaster response.[68]

[62] http://eur-lex.europa.eu/LexUriServ/site/en/oj/2006/c_146/c_14620060622en00040005.pdf
[63] http://www.europarl.europa.eu/charter/pdf/text_en.pdf
[64] http://ec.europa.eu/health/strategy/docs/ev_20090428_rd01_en.pdf
[65] Schröder-Bäck, Timo Clemens, Kai Michelsen, Tobias Schulte in den Bäumen, Kristine Sørensen, Glenn Borrett and Helmut Brand, "Public health ethical perspectives on the value of the European Commission's White Paper "Together for Health", *Cent Eur J Public Health*, Vol. 2, 2012, pp. 95-100.
[66] Ibid, p. 99.
[67] http://europa.eu/legislation_summaries/public_health/european_health_strategy/sp0017_en.htm
[68] Kenny et al., op. cit., September-October 2006, p. 403.

The objective of health protection aims to minimise threats to health through collective action such as safe food, water, drugs, workplace and environment.[69] The relevant ethical issue here concerns the values or principles on which decisions regarding the balance of individual freedom and public safety should be made, in addition to the levels of coercion that are acceptable.[70] The fluoridation of water for public health – the controlled addition of fluoride to water is thought to reduce tooth decay – is one area in which this question arises. Water fluoridation can be justified by the following: the reduction of health inequalities, the reduction of ill health and concern for children as a particularly vulnerable group.[71] On the other hand, the principles of avoiding coercive interventions and minimising interventions in personal life could be used to argue against the addition of any substance to the water supply.[72] Consent is another relevant ethical issue here.[73]

Health surveillance necessitates ongoing, population-based data collection.[74] Privacy and confidentiality are vital for maintaining public trust here. Ethical questions to be addressed in this context include the following: On what grounds can confidentiality be breached? Where is the line between public safety and individual privacy? Could communities and groups be targeted for discrimination?

Disease and injury prevention requires a balancing of collective and individual good. The main ethical issue here concerns how to justify possible risks to individuals as a result of mandatory screening, immunisation and treatment.[75]

Health promotion involves respecting the delicate balance between individual and social responsibility for health.[76] There is a need for voluntariness in health education, health promotion and public health communication programmes.[77] The risks and potential harms of public health interventions include ineffective, counterproductive or harmful interventions, unanticipated consequences and labelling or stigmatising of individuals.[78] As regards the latter, for example, public health activity in the area of preventing obesity and over-eating is faced with the challenge of addressing questions such as whether a campaign that stresses the importance of a healthy weight is acceptable when it stigmatises people who are overweight.[79] Thus a major dilemma in this area concerns how to advise people that they might be at risk of potentially serious health complications without labelling them, contributing to their anxiety or adversely affecting their well-being.[80]

Disaster response raises many issues including the balancing of civil liberties with community safety and the duties of health care workers.[81] These issues gained particular prominence with

[69] Ibid., p. 403.
[70] Ibid.
[71] Nuffield Council on Bioethics, op. cit., 2007.
[72] Ibid.
[73] Nuffield Council on Bioethics, op. cit., 2007.
[74] Kenny et al., op. cit., 2006, p. 403.
[75] Ibid., p. 404.
[76] Kenny et al., op. cit., 2006, p. 404.
[77] Coughlin, Steven S., "Ethical issues in epidemiologic research and public health practice", *Emerging Themes in Epidemiology*, Vol. 3, No. 16, 2006, doi:10.1186/1742-7622-3-16
[78] Ibid.
[79] ten Have, Marieke, de Beaufort, Inez, D. , Mackenbach, Johan, P. and Agnes van der Heide, "An overview of ethical frameworks in public health: can they be supportive in the evaluation of programs to prevent overweight?, BMC Public Health, Vol. 10, No. 638, 2010.
[80] Coughlin, op. cit., 2006, p. 403.
[81] Kenny et al., op. cit., 2006, p. 403.

the Severe Acute Respiratory Syndrome (SARS) epidemic when public health protections were found wanting.[82] The worldwide threat of SARS in 2002 posed the question of when, in the name of public health, individuals and communities could be deprived of their liberty.[83] Liberty is at stake when quarantine measures are being considered.[84] The extent to which healthcare workers are obligated to risk their lives in delivering clinical care during an infectious disease epidemic is an ethical issue associated with duty of care.[85] Finally, allocation of resources in disasters requires healthcare workers to distribute resources such that the "greatest good for the greatest number" can be achieved.[86]

4 ORGANISATIONS

The European Commissions' directorate for public health and risk assessment[87] falls under the Directorate General for Health and Consumers (DG SANCO). The directorate for public health and risk assessment includes a focus on programme management and diseases, health information, health threats, and health determinants. As regards public health policy including ethics, Health Technology Assessment (HTA) offers a means of assessing the ways in which science and technology are used in healthcare and disease prevention. HTA covers ethical issues, in addition to medical, social and economic issues. In order to enhance cooperation between countries, the Commission has set up a permanent, voluntary HTA network in Europe.[88]

The European Public Health Association (EUPHA)[89] is an umbrella organisation for public health associations and institutes in Europe. EUPHA was founded in 1992 by 15 members (12 countries) and now has 71 members from 40 countries. EUPHA encompasses sections for specific public health themes which are international in scope and open to all public health experts. In 2008, a section on Ethics in public health was created and now has nearly 750 members.[90]

The Centers for Disease Control and Prevention (CDC) pursue public health ethics activities in order to integrate the tools of ethical analysis into day-to-day operations across CDC. Two public health ethics committees provide leadership for this activity at CDC, namely the CDC Public Health Ethics Committee (PHEC) and the Ethics Subcommittee of the Advisory Committee to the Director, CDC. PHEC is responsible for creating CDC's public health ethics infrastructure, including providing tools for analysing ethical issues, raising staff awareness of public health ethics and fostering an environment and culture that supports and develops ethical practices. The external Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) comprises experts in ethics and related fields drawn from outside CDC who work closely with CDC officials responsible

[82] Wickler and Brock, op. cit., 2007, p. 90.
[83] Bayer and Fairchild, op. cit., 2004, p. 483.
[84] Annas, George J., "Your liberty or your life", *EMBO reports*, Vol. 8, No. 12, 2007, pp. 1093-1098.
[85] Singer, Peter A., R. Benatar Solomon,, Mark Bernstein,, Abdallah S. Daar, Bernard M., Susan K. MacRae, Ross E.G. Upshur,, Kinda Wright and Randi Zlotnick Shaul, "Ethics and SARS: lessons from Toronto", *BMJ*, Vol. 327, 6 December 2003, pp. 1342-1344 [p. 1343].
[86] Hick, John, L., Dan Hanfling and Stephen V. Cantrill, "Allocating Scarce Resources in Disasters: Emergency Department Principles", *Annals of Emergency Medicine*, Vol. 59, No. 3, March 2012, pp. 177-186 [p. 177].
[87] http://ec.europa.eu/health/index_en.htm
[88] http://www.eunethta.eu/about-us
[89] http://www.eupha.org/site/history.php
[90] See http://www.eupha.org/site/section_page.php?section_ref=S_EPH

for public health ethics consultation within CDC and with CDC experts from National Centers who advise on specific issues or content areas.[91]

The World Health Organization (WHO)[92] is the directing and coordinating authority for health within the United Nations system. WHO is responsible for providing leadership on global health matters, shaping the health research agenda and setting norms and standards, amongst other mission activities. In 2008, the WHO released a special issue of its *Bulletin* on public health ethics.[93] In its Eleventh General Programme of Work (2006-2015)[94], the WHO listed one of its core functions as articulating ethical and evidence-based policy options.

The Public Health Leadership Society (PHLS) is a membership organisation in the United States comprising alumni from national, state and regional public health leadership institutes.[95] In 2002, funded by the CDC and the PHLS, the Principles of the Ethical Practice of Public Health were developed by the Center for Health Leadership & Practice, Public Health Institute, members of the original PHLS Ethics Work Group and the current PHLS standing committee on Public Health Ethics (see section 6).

The American Public Health Association works to improve the health of the public and achieve equity in health status.[96] The American Public Health Association Ethics Special Primary Interest Group provides opportunities to public health practitioners and students to connect and collaborate with colleagues committed to advancing public health ethics in practice, teaching and research.[97]

In 2003, the Association of Schools and Programs of Public Health (ASPPH) created a resource – a model curriculum on ethics and public health – to enhance and encourage thoughtful, well-informed and critical discussions in the field of public health. Modules include "Tradition, Profession and Values in Public Health", "Public Health Research and Practice in International Settings" and "Ethical Issues in Environmental and Occupational Health", amongst others. The curriculum is freely available online.[98]

The UNC Gillings School of Global Health in North Carolina aims to improve public health, promote individual well-being and eliminate health disparities across North Carolina and around the world.[99] The School has developed a public health ethics course[100] aimed at graduate students in public health and working public health professionals. The course was developed in order "to promote the ethical practice of public health by teaching about the ethical principles of public health and by providing resources for creating an ethical climate in public health agencies and schools of public health".

The International Association of Bioethics (IAB)[101] has established an international Public Health Ethics Network[102] which has the following aims: (i) to raise the profile of public health

[91] http://www.cdc.gov/od/science/integrity/phethics/
[92] http://www.who.int/about/en/
[93] http://www.who.int/bulletin/volumes/86/8/08-055954/en/
[94] See http://whqlibdoc.who.int/publications/2006/GPW_eng.pdf
[95] http://www.phls.org/home/
[96] http://www.apha.org/about/
[97] http://www.apha.org/membergroups/primary/aphaspigwebsites/ethics/
[98] http://www.asph.org/document.cfm?page=782
[99] http://sph.unc.edu/resource-pages/about-sph/
[100] http://oce.sph.unc.edu/phethics/modules.htm
[101] http://bioethics-international.org/index.php?show=objectives

ethics as an area of research (within the IAB and in the academic environment in general); (ii) to encourage and actively engage in research and debate about ethical issues in public health policy and practice and (iii) to encourage and facilitate international research collaborations in the area of public health ethics. The Public Health Ethics Network is co-ordinated by two well-known scholars in the public health ethics field, Angus Dawson and Marcel Vermeij.

5 INSTITUTIONALISATION

Ross Upshur, an early public health ethics pioneer, reflecting in 2012 on the development of public health ethics, made this observation:

> Twenty years ago, during my community medicine residency, I was struck by the number of ethical issues that arose in routine public health practice…. While ethical issues and concerns were in abundance, however, one was hard pressed to find a space to discuss the issues and scant resources to assist deliberating on the issues or in advancing one's learning. Aside from the occasional book chapter and a rather vigorous debate centred on HIV/AIDS, there were no courses, no textbooks, few articles and even less appetite for discussion on public health ethics issues…. Twenty years on, things have changed. Recent public health events, such as the SARS outbreak and the Walkerton e-coli outbreak, as well as the growing obesity problem and recognition of the ongoing disparities in health both in Canada and globally, have reinforced the need for ethical reflection in practice.[103]

While public health ethics attracted attention only in the late 1990s and 2000s, the field is gaining momentum. The years since 2000 have been especially productive, generating a journal dedicated to public health ethics[104], many books[105] and technical reports[106]. Public health ethics curricula have been developed in the United States (see section 4). Global and national public health organisations have also put public health ethics on the agenda. The World Health Organization released a special issue of its *Bulletin* on public health ethics (see section 4). The US Centers for Disease Control and Prevention (CDC) has established a CDC Public Health Ethics Committee (see section 4).

A dedicated public health ethics network has been established by the International Association of Bioethics (see section 4). Research institutes dedicated to the study of public health ethical issues include The Center for the History and Ethics of Public Health at Columbia University.[107] Some research institutes such as the Ethics Institute at the University of Utrecht consider ethical issues of public health, amongst other topics. [108] The London School of Hygiene & Tropical Medicine has established an International Programme for Ethics, Public Health and Human Rights which acts as an interdisciplinary forum within the

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[102] http://bioethics-international.org/index.php?show=networks

[103] Upshur, Ross E.G., "Setting the Stage: Population and Public Health Ethics *or* Public Health Ethics: Ineffable, Ignorable or Essential?" in Canadian Institutes of Health Research – Institute of Population and Public Health, *Population and Public Health Ethics: Cases from Research, Policy, and Practice*, University of Toronto Joint Centre for Bioethics, Toronto, Ontario, 2012, pp. 11-20.

[104] http://www.oxfordjournals.org/our_journals/phe/about.html

[105] Holland, S., *Public Health Ethics and Practice*, Polity Press, Cambridge, 2007; Dawson, Angus, and Marcel Verweij (eds.), *Ethics, prevention and public health*, Clarendon Press, Oxford, 2007; Peckham, Stephan A., and Allison Hann (eds.), *Public Health Ethics and Equity*, Policy Press, Bristol, 2010.

[106] Nuffield Council on Bioethics. "Public health: ethical issues", Nuffield Council on Bioethics, London, 2007.

[107] http://www.mailman.columbia.edu/academic-departments/centers/center-history-and-ethics-public-health

[108] http://www.uu.nl/faculty/humanities/EN/organisation/departments/department-of-philosophy-and-religious-studies/EthicsInstitute/Pages/default.aspx

School and combines research, teaching and practical work around ethical dimensions of public health.[109] Johns Hopkins Bloomberg School of Public Health offers a PhD programme in Bioethics and Health Policy which focuses on bioethics as it relates to moral questions in public health and health policy, as opposed to clinical medicine.[110]

Notwithstanding these impressive developments in the public health ethics effort, there appears to be little institutionalised ethics assessment as regards standard-setting of ethics assessment for public health. The most frequently referred to code of public health ethics is the Public Health Code of Ethics developed by the Public Health Leadership Society (see section 6). Additional guidelines encountered during the research are listed in section 6.

6 INTERNATIONAL FRAMEWORKS AND PROTOCOLS

There appears to be only one widely recognised set of principles in public health ethics, i.e., the set of principles developed by the Public Health Leadership Society. The others encountered during our research were primarily concerned with preparation for pandemics and other emergency situations.

- Public Health Leadership Society, "Principles of the Ethical Practice of Public Health Version 2.2", 2002.[111] The Code highlights the ethical principles that follow from the distinctive characteristics of public health with the interdependence of people a key belief underlining several of the principles. The Code is intended primarily for public and other institutions in the United States that have an explicit public health mission.
- World Health Organization, "Ethical considerations in developing a public health response to pandemic influenza", 2007.[112] The purpose of this document is to assist social and political leaders at all levels who influence policy decisions regarding the incorporation of ethical considerations into national influenza pandemic preparedness plans.
- The "Ethical Guidelines" section of the US Centers for Disease Control and Prevention (CDC) website has links to documents that have identified ethical considerations relevant to public health decision-making during planning for and responding to pandemic influenza.[113]
- Members of the Bellagio Group, Bellagio Statement of Principles, 2006.[114] The Members of this Group have issued a Statement of Principles for incorporating considerations of social justice in pandemic planning response.
- O'Malley, P., J. Rainford and A. Thompson, "Transparency during public health emergencies: from rhetoric to reality", *Bulletin of the World Health Organization*, Vol. 87, No. 8, 2009, pp. 614-618.[115]
- University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group, "Stand on Guard for Thee: Ethical considerations in preparedness planning for

[109] http://ipeph.lshtm.ac.uk/overview.html
[110] http://www.jhsph.edu/departments/health-policy-and-management/degrees-programs/phd-in-bioethics-and-health-policy/
[111] http://www.apha.org/NR/rdonlyres/1CED3CEA-287E-4185-9CBD-BD405FC60856/0/ethicsbrochure.pdf.
[112] http://www.who.int/csr/resources/publications/WHO_CDS_EPR_GIP_2007_2c.pdf?ua=1
[113] http://www.cdc.gov/od/science/integrity/phethics/ESdocuments.htm
[114] http://www.unicef.org/avianflu/files/Bellagio_Statement.pdf
[115] http://www.who.int/bulletin/volumes/87/8/08-056689.pdf

pandemic influenza", November 2005.[116] The members of this working group developed a 15-point ethical guide for planning and decision-making for a pandemic. They identified four key ethical issues that need to be addressed in pandemic planning – healthcare workers' duty to provide care, restriction of liberty by measures such as quarantine, priority setting, including the allocation of scarce resources and global governance implications such as travel advisories – and made specific recommendations for each.

- United States Institute of Medicine, "Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations", 2009.[117] This report provides concepts and guidance to assist state and local public health officials, healthcare facilities, and professionals in the development of systematic and comprehensive policies and protocols for crisis standards of care in disasters where resources are scarce.

7 JOURNALS AND CONFERENCE SERIES

- *American Journal of Public Health*[118]
- *Annual Review of Public Health* [119]
- *BMJ*[120]
- *Bulletin of the World Health Organization*[121]
- *Canadian Journal of Public Health*[122]
- *Journal of Public Health Management and Practice*[123]
- *Public Health*[124]
- *Public Health Ethics*[125]
- *The Journal of Law, Medicine and Ethics*[126]
- *The Lancet*[127]

Conference series

- European Public Health Conferences[128]
- World Federation of Public Health Associations International Congress on Public Health[129]
- World Congress on Public Health[130]
- World Congress of Bioethics[131]
- IEA World Congress on Epidemiology[132]

[116] http://www.jointcentreforbioethics.ca/people/documents/upshur_stand_guard.pdf
[117] http://www.nap.edu/catalog.php ?record_id=12749
[118] http://ajph.aphapublications.org/
[119] http://www.annualreviews.org/journal/publhealth
[120] http://www.bmj.com/
[121] http://www.who.int/bulletin/en/
[122] http://www.cpha.ca/en/cjph.aspx
[123] http://journals.lww.com/jphmp/Pages/default.aspx
[124] http://www.journals.elsevier.com/public-health/
[125] http://phe.oxfordjournals.org/
[126] http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1748-720X
[127] http://www.thelancet.com/
[128] http://www.eupha.org/site/general.php?page=5
[129] http://www.wfpha.org/events.html
[130] http://www.14wcph.org/
[131] http://bioethicsmexico.mx/

8 KEY PUBLICATIONS

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[132] https://www.signup4.net/Public/ap.aspx?EID=201445E&TID=xVmvSUI6Zg24ZpxTdbULQw%3d%3d