Chapter 4
Disease Prevention and Control

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4.1 Introduction

Ethical issues surrounding public health policy and practice regarding disease prevention and control often involve conflicting rights and values. Such conflicts partly arise from tension between individual and community interests or tension involving cultural beliefs and practices. This chapter outlines how such conflicts and tensions arise in the context of disease prevention and control by exploring ethical issues associated with mandatory treatment and vaccination, disease screening and surveillance, diseases prone to stigma, access to care, health promotion incentives, and emergency response.

4.2 Mandatory Treatment and Vaccination

In standard biomedical ethics (as opposed to public health ethics) discourse, the patient's right to informed consent to medical intervention is often considered sacrosanct. A primary aim of informed consent is to avoid medical paternalism, such as coercing a patient to do something for his or her own benefit. The transition in clinical practice from medical paternalism to informed consent was largely based on the ideas that (1) a well-informed patient is better placed than the doctor to determine which actions are in the patient's best interests (Goldman 1980) and (2) that a patient's autonomy should, in any case, be respected.

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In public health, however, treatment and vaccination may, in addition to the health of the individual, be important to population health. As such, individual patients are not the only stakeholders whose interests must be considered. In the context of tuberculosis (TB), coercive treatment is common—in so far as, in many jurisdictions, patients with active TB are required to undergo (often directly observed) treatment under threat of confinement if they refuse. While TB treatment usually benefits those subjected to this kind of coercion, the primary motive for such policies is the protection of public health rather than paternalism. Because patients with untreated active TB remain contagious, their treatment is essential to prevent infection of others. Though objections to paternalism are not as relevant to mandatory treatment in this context, ethical issues remain. Because mandatory treatment (aimed at protection of others) conflicts with individual liberty, there is a conflict between legitimate values—i.e., individual liberty versus public health. There are also conflicting rights—i.e., the right of coerced individuals to autonomy versus the rights of others to health (or their rights not to be harmed by being infected). Each of these values and rights is legitimate; and, arguably, none should be given absolute priority over the others. A key ethical question about mandatory treatment is, thus, how great the threat to others (and public health in general) would need to be in order for mandatory treatment to be justified.[1] It is noteworthy that TB is relatively exceptional—i.e., there are not many other cases of infectious diseases for which treatment is routinely required.

Similar issues arise in the context of vaccination. While vaccination usually benefits the vaccinated, it also benefits others via contribution to herd immunity (Verweij and Dawson 2004). Mandatory vaccination is also more common than mandatory treatment. In some jurisdictions, for example, vaccination of children is required for school attendance. The case presented by Simón-Lorda et al. considers the scenario of a measles outbreak, resulting from a low rate of vaccination uptake, at a school in Spain. In the scenario, the conflicting rights associated with mandatory medical intervention again come into play. The suggestion that unvaccinated children should not be permitted to attend school, for example, is initially rejected by health authorities on the grounds that this would conflict with their right to education. Unvaccinated children's right to education, thus, conflicts with the rights of other children not to be infected. How should such a conflict of rights be resolved? In the case presented by Simón-Lorda et al., the outbreak finally becomes so widespread that mandatory vaccination is called for as an emergency measure. Assuming such a decision would be legitimate in the scenario under consideration, it might be grounded on the belief that public health outweighs individual liberty when the stakes are sufficiently high (rather than the belief that the value of public health outweighs the value of liberty in general).

A complicating factor regarding mandatory vaccination is that when one unvaccinated child ends up becoming infected with a disease (such as measles) and then goes on to infect others, it could be argued that those others who become infected do not in fact have their rights violated because they could have avoided infection

[1] With respect to the public health ethics framework discussed in Chap. 1, the question here is what, exactly, the proportionality requirement should be thought to consist in. For further discussion of this issue, see Selgelid (2009).

by getting vaccinated themselves. It would usually be parents, rather than children, however, who make decisions about childhood vaccination. This raises the question of who (e.g., parents or the government) should have authority to make decisions about children's health and well-being—and vaccination in particular. Assuming that parents should usually retain decision-making authority about childhood vaccination, the relevance of cultural differences to public health ethics is highlighted by the fact that some parents may refuse vaccination of their children for what are ultimately cultural reasons (e.g., religious beliefs). This leads to questions (also raised by other cases presented in this chapter) about whether, and to what extent, cultural beliefs and practices should influence public health policy and practice.

4.3 Disease Screening and Surveillance

As in the cases of treatment and vaccination, informed consent to diagnostic testing is usually considered essential in standard biomedical ethics discourse regarding doctor-patient relationships. In public health, however, diagnostic testing is sometimes required, for example as a condition of employment (such as tuberculin skin testing of restaurant and hospital employees) or immigration (for which both TB and HIV testing are common). Testing of tissues or other biological samples also sometimes takes place, for research or surveillance purposes, without patients' or donors' awareness or consent (e.g., testing of stored sputum samples to determine TB drug resistance prevalence). Cases such as these may pose conflict between the goal to promote public health, on the one hand, and the goals to respect individual autonomy and privacy, on the other. As with mandatory treatment and vaccination, however, such practices are arguably justifiable in cases where public health benefits are sufficiently high (which is not to say that public health generally trumps autonomy and privacy).

As with vaccination, questions about parental authority in decision making regarding childhood health arise in the context of disease screening. The case presented by Nicholls et al., raises such issues. Bloodspot screening is commonly used to test newborns for numerous serious health conditions, and stored bloodspots are sometimes later used for research and surveillance that lead to important public health benefits. Given the potential importance of such practices for a child's health, and to public health more generally, to what extent is parental informed consent to bloodspot screening or secondary use of stored bloodspots essential? The case presented by Nicholls et al. raises the worry that more parents, out of privacy concerns, might refuse newborn bloodspot screening if a thoroughgoing informed consent process (as opposed to the current opt-out model) were required, and that this could have adverse effects for both newborns and, given the benefits of research and surveillance with stored bloodspots, public health more generally. Among other important questions, Nicholls et al. ask, "How should clinically actionable results [of secondary investigations involving bloodspots] be dealt with?" When surveillance testing of stored bloodspots or other stored tissues leads to identification of not-previously-recognized disease (or predispositions thereto), for example, to what extent do investigators have duties to track down and inform individuals from whom

bloodspots or other stored tissues were originally obtained? Like research, surveillance raises ethical issues about standards of care (Selgelid 2012).

Ethical issues concerning testing and surveillance are also highlighted in the case presented by Bhattacharya. In this case, the criminalization of HIV transmission and mandatory name-based reporting requirements (in the case of HIV diagnosis) are portrayed as deterrents to sex workers' seeking of HIV testing. In the case of criminalized transmission, the disincentive to testing is that criminal penalties associated with prostitution are greater (in some jurisdictions) for those who have tested HIV positive. Among other things, criminalizing HIV makes it difficult for public health workers to promote HIV testing of sex workers (who are an especially vulnerable group, and for whom testing is especially important—for their own sake and for public health more generally) while adhering to mandatory reporting requirements. This challenge is further exacerbated by socio-economic and cultural factors that promote prostitution to begin with.

This case also raises more general issues about the criminalization of infectious disease transmission. Many argue that there is a moral obligation to avoid infecting others, based on a duty not to harm others (Harris and Holm 1995). Criminalizing infectious disease transmission involves the legal enforcement of such a moral duty. Given that HIV transmission usually involves consenting adults knowingly taking risks, one might question whether criminalization of HIV transmission, in particular, is necessary. It should be noted, however, that it is usually *intentional* transmission of HIV that is criminalized. In any case, criminalization of HIV transmission raises questions about the extent to which intentional transmission of other diseases should also be criminalized and whether, or why, *negligent* transmission (of HIV or other diseases) should also be subject to legal penalties.

The case by Bhattacharya also raises ethical questions about name-based reporting, which is legally required upon positive diagnosis of numerous diseases of public health importance (Fairchild et al. 2007). As a surveillance measure, the purpose of name-based reporting pertains to contact tracing and, among other issues, estimations of disease incidence or prevalence, which are used to inform public health policy and practice (Lee et al. 2010). While mandatory name-based reporting may have important public health benefits, it conflicts with privacy and informed consent. It may also have adverse effects upon public health if it ends up driving epidemics underground, when those especially in need of testing and treatment are reluctant to seek care due to concerns about privacy or lack of trust in health care providers. What the overall public health consequences of name-based reporting actually are, with any reportable disease, is ultimately an empirical question.

4.4 Stigma

Related to the privacy issues considered above is the problem of disease stigmatization, which can lead to discrimination and other abuses of those known (or, perhaps wrongly, believed) to be affected. The extent and nature of disease stigmatization, and the effects thereof, are often largely related to cultural factors or misunderstanding of

the diseases in question. The unjust discrimination and abuse commonly associated with disease stigmatization are especially problematic because they make matters worse for those who are already badly off (by virtue of health status). As in the case considered above, stigma can also deter those in need from seeking testing or health care to begin with. The problem of stigma could be reduced via better public education about the nature of stigmatized diseases and better legal protections against unjust discrimination and other abuses associated with stigma.

Ways in which stigmatization can interfere with individual and public health is illustrated in the case presented by Henning and Nair. While risks of vertical HIV transmission from infected mother to newborn can be reduced by replacing breastfeeding with formula and providing antiretrovirals to the mother, in some southern African countries HIV is so heavily stigmatized that women may be reluctant to pursue such measures in fear they will suffer violence or be abandoned by their husbands (if such measures reveal, or raise suspicions about, their HIV status). In the case presented by Henning and Nair, such fears on the part of a mother create a dilemma for her doctor, who, based on best medical practice and concern for the baby (and public health), would presumably want to encourage such measures, but, based on concern for the mother's privacy and well-being, might not want to insist on them. While there is no obvious answer to the question of what the doctor should immediately do in this poignant case presented by Henning and Nair, the long-term solution to this kind of problem would presumably require cultural change involving reduction of HIV stigma via public engagement and awareness-raising, and greater empowerment and protection of women in general.

4.5 Access to Care

It is commonly believed that there is a universal human right to health and/or health care, and such rights are enshrined by the *Universal Declaration of Human Rights* and other human rights instruments (Selgelid and Pogge 2010). In addition to being a matter of human rights and justice, access to care is also important for public health. In the context of infectious diseases, for example, lack of access to care results in perpetuation of epidemics when those left untreated remain contagious. This is one reason the burden of infectious disease is more heavily shouldered by impoverished developing nations, where access to care is limited, largely due to resource constraints. When such diseases run rampant in developing countries, this poses threats to global health more generally—because infectious diseases show no respect for international borders. This points to self-interested reasons, in addition to egalitarian and human rights reasons, for wealthy countries to do more to promote health care improvement in developing countries.

Although the right to health care is widely recognized (if not always well respected and protected) it is questionable whether such a right should be considered absolute. Some means of health care may be too expensive, even in wealthy countries, to be routinely provided. In other cases, providing health care to individual patients might itself have adverse effects on public health. When patients fail to complete a full

course of antimicrobial treatment, for example, this promotes emergence of drug resistance (which increases danger to others who might be infected). Luco et al. present a case involving a TB patient who repeatedly fails to complete his prescribed course of medication and ends up with drug-resistant TB as a result. In light of this patient's history of noncompliance, his adherence to further courses of treatment might be considered unlikely. The patient nonetheless pleads for a new course of treatment and promises to adhere to the prescribed regimen. Whether providing additional treatment in a case like this would be warranted depends at least partly on whether there is a decent chance the treatment will succeed (assuming the patient does in fact adhere) in light of the current level of drug resistance. If the patient's TB is already resistant to all available treatments, then further treatment (even if the patient adheres) might at best be futile or at worst lead to greater drug resistance.

If, on the other hand, the patient's TB remains susceptible to treatment then deciding whether to provide additional medication might partly depend on the likelihood that the patient will comply with treatment in the future. One might argue that a doctor's decision to withhold treatment based on predictions about continued noncompliance would involve unjust discrimination based on the doctors' judgment of the patient's character, and that doctors, in general, have no special expertise for making such judgments or predicting patients' behavior in the first place (World Health Organization [WHO] 2010). If the patient is left untreated, then this would arguably infringe on his right to health care and threaten public health (i.e., if the patient remains infectious and at large in the community). On the other hand, based on past experience, there appears to be a legitimate concern that providing care (or respecting the patient's right to care) may conflict with others' right to health and public health more generally (i.e., as continued noncompliance may lead to increased drug resistance). Consideration of this case motivates further reflection on mandatory treatment (discussed above) because if treatment compliance was better enforced to begin with, then dilemmas posed by cases like this might be avoided.

4.6 Health Promotion Incentives

Public health policies often involve incentivizing health promoting behaviors (e.g., provision of financial benefits to parents when children are vaccinated) and/or disincentivizing unhealthy behavior (e.g., heavy taxation of things like cigarettes and alcohol). While such policies might be considered manipulative or paternalistic in spirit, they do not rely on outright coercion if people are still ultimately free to behave as they wish, and so autonomy is largely respected. Their legitimate aim is health improvement. Such policies, however, may sometimes involve tension with cultural beliefs and practices. In the case presented by Bhati, for example, cash incentives are used to encourage childbirth in health care institutions in India, where homebirth remains traditional. This situation leads to a tragic conclusion in the case of a mother who resists her in-laws' pressure (apparently based on monetary motive) toward institutional delivery. She ends up losing her child due to delivery

complications while traveling to her home village where she planned to give birth and is then faced with "the wrath of her husband and in-laws." While the cash incentive aims to promote the health of mothers and children, and public health more generally, the point of this case is to show how this kind of health promotion incentive might exacerbate pressures on women who, in the cultural milieu of India, already suffer diminished autonomy. The warning is that, despite good intentions, health promotion incentives can backfire if they lack adequate cultural sensitivity.

4.7 Emergency Response

Emergencies are extreme situations (Viens and Selgelid 2012) where threats to public health can be exceptionally severe. Examples include epidemics, other natural disasters (e.g., floods, hurricanes, earthquakes), and manmade disasters (e.g., war, terrorism, severe environmental damage). As noted in cases previously discussed, public health policies and practices often give rise to conflicts between the rights and liberties of individuals, on the one hand, and the goal to promote public health, on the other. It has also been repeatedly suggested (above) that the importance of public health protection is more likely (than would otherwise be the case) to outweigh the importance of protecting/respecting individual rights and liberties in cases where the magnitude of threat to public health is especially great. During emergencies, therefore, it may be more necessary than in other contexts to resort to liberty infringing measures. In the case of a severe epidemic, for example, social distancing measures such as isolation and quarantine might be justified despite the fact that they interfere with one of the most basic human rights, freedom of movement.

Emergencies also often put unprecedented pressure on limited resources and thus require difficult ethical decisions regarding resource allocation. Given the spectre of a future severe influenza pandemic, for example, there has been much debate about who should be given priority for resources like antivirals, vaccines, and ventilators if (as may be expected) need outstrips supply (Verweij 2009).

Emergencies, finally, also often call for urgent action. So, decisions must be made quickly, and other time-saving measures may be needed to mitigate harm. While urgent research might be needed to understand and control an epidemic caused by a novel pathogen, for example, it has been argued that the usual procedures for ethical clearance of research (which can be very slow) might need to be altered in the case of emergency research in particular (WHO 2009).

The issue of urgency is well illustrated by the case presented by Peacock and colleagues. In the event of a major bioterrorist attack involving anthrax, it might be necessary to vaccinate large numbers of people quickly. Administration of vaccine shortly after exposure is important because anthrax vaccine provides prophylactic protection. Because anthrax vaccine has not been tested in children, however, its use in children would require informed consent of parents according to U.S. law. In a scenario where huge numbers of children would need to be vaccinated quickly, however, going through usual informed consent processes might take too much time (and perhaps

lead to unrest among those waiting to be vaccinated). This motivates examination of possible ways to hasten the consent process, for example, via group information sessions rather than the usual one-on-one consent process. While group consent procedures may facilitate more timely vaccination of children, the question is whether, or the extent to which, group sessions would ultimately compromise informed consent and whether such compromise would be justified by public health benefits. As with other cases presented in this chapter, the case presented by Peacock et al. illustrates how cultural factors may pose special difficulties. For example, quick consent would be especially challenging in cases where children's parents do not speak English. Quick consent (to a vaccine that has not been studied in children) may likewise be difficult in cases where parents are generally skeptical about vaccine safety.

The case presented by Viens and Smith explores a range of ethical challenges associated with mass evacuation that might be called for in an emergency scenario involving a major hurricane. Among other issues, this case raises questions about when evacuation should be voluntary or mandatory (while the latter, like isolation and quarantine, would involve interference with freedom of movement); whether, or how, mandatory evacuation should be enforced; whether there are duties to rescue those who refuse to comply with calls for evacuation; whether such people should be financially sanctioned if they are in fact rescued; who should be given special assistance with evacuation efforts, and how those in need of assistance should be prioritized; whether it might be acceptable to abandon unstable patients who cannot be moved (or for whom movement would be excessively expensive); whether compensation might be due to those who suffer financial (or other) loss as a result of compliance with calls for voluntary or mandatory evacuation; and whether there should be legal protections against price gouging of commodities like gasoline.

4.8 Conclusion

This chapter has illustrated ways in which ethical issues associated with disease prevention and control involve conflicting rights and values, tensions between individual and community interests, and tensions involving cultural beliefs and practices. While the cases discussed in this chapter provide a good overview of many of the most important and difficult ethical issues associated with disease prevention and control, the discussion above reveals that their resolution would require resolution of both empirical questions (about the extent to which alternative values would likely be promoted or compromised by one practice or policy or another) and philosophical questions (about how to balance legitimate values in cases of conflict). It is also important to recognize that resolution of any of the specific issues in the cases discussed above would not necessarily imply resolution of the more general issues raised by these cases. Resolving the question of whether or not there should be mandatory measles vaccination in Spain, for example, would not resolve the question of whether there should be mandatory vaccination of measles in other countries, or whether there should be mandatory vaccination against other diseases (in Spain or elsewhere). A virtue of case studies is that context is crucial to the empirical questions that ethical issues (partly) turn on.

References

Fairchild, A.L., R. Bayer, and J. Colgrove. 2007. *Searching eyes: Privacy, the state, and disease surveillance in America*. Berkeley: University of California Press.

Goldman, A. 1980. *The moral foundations of professional ethics*. Totowa: Rowman and Littlefield.

Harris, J., and S. Holm. 1995. Is there a moral obligation not to infect others? *British Medical Journal* 311: 1215–1217.

Lee, L.M., S.M. Teutsch, S.B. Thacker, and M.E. St. Louis (eds.). 2010. *Principles and practice of public health surveillance*. New York: Oxford University Press.

Selgelid, M.J. 2009. A moderate pluralist approach to public health policy and ethics. *Public Health Ethics* 2(2): 195–205.

Selgelid, M.J. 2012. Case discussion in response to obesity surveillance in school children. In *Population and public health ethics: Cases from research, policy, and practice*, 26–31. Toronto: University of Toronto Joint Centre for Bioethics.

Selgelid, M.J., and T. Pogge. 2010. *Health rights*. Farnham: Ashgate.

Verweij, M. 2009. Moral principles for allocating scarce medical resources in an influenza pandemic. *Journal of Bioethical Inquiry* 6(2): 159–169.

Verweij, M., and A. Dawson. 2004. Ethical principles for collective immunisation programmes. *Vaccine* 22(23–24): 3122–3126.

Viens, A.M., and M.J. Selgelid. 2012. *Emergency ethics*. Farnham: Ashgate.

World Health Organization (WHO). 2009. *Research ethics in international epidemic response*. Geneva: World Health Organization. http://www.who.int/ethics/gip_research_ethics_.pdf. Accessed 5 Nov 2013.

World Health Organization (WHO). 2010. *Guidance on ethics of tuberculosis prevention, care and control*. Geneva: World Health Organization. http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf. Accessed 5 Nov 2013.

4.9 Case 1: Mandatory Vaccination in Measles Outbreaks

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4.9.1 Background

In 2005, the European Regional Office of the World Health Organization (WHO-EUR), which includes 53 countries, set the goal of eliminating measles in Europe in 2010 (WHO 2005). The Pan American Health Organization (PAHO) declared the WHO Region of the Americas free from endemic measles in 2002 (Castillo-Solorzano et al. 2011). Nevertheless, that region has continued to experience periodic outbreaks, probably due to importation of measles from other parts of the world. In 2008, WHO's Executive Board (EB) began to determine whether to extend the goal of eradicating measles to the rest of the world (WHO 2010a).

The decrease in measles cases after a vaccine was introduced in the 1980s made the WHO-EUR goal of eliminating measles in Europe realistic. However, in 2006–2007, the vaccine coverage rates remained below 90 % in many European countries, and although the number of cases continued to fall, epidemic outbreaks still occurred periodically (Muscat et al. 2009). At the end of 2009, an explosion of outbreaks was recorded and the number of cases began to increase sharply. This upward trend continued throughout 2010, when 30,639 measles cases were reported (WHO 2011). This forced WHO-EUR to postpone its eradication goal until 2015 (WHO 2010b).

The increase in measles cases can be attributed to the inability to achieve appropriate levels of vaccine coverage (>90 %) either because people cannot access health services, or because they hold personal beliefs against vaccination (Muscat 2011). The latter group includes members of the anti-vaccination movement, which makes extensive use of the Internet and social networks to share ideas (Kata 2010). After rumors spread about an association between measles vaccination and autism, vaccine coverage rates decreased in countries such as the United Kingdom, where "anti-vaccination" sentiment has gradually grown during the past 10 years (Flaherty 2011).

Measles is a notifiable disease in the 53 WHO-EUR countries, all of which employ a two-dose regimen for immunization. However, measles vaccination is not mandatory in all WHO-EUR countries. A study of 29 of the 53 WHO EUR member countries showed that, in 2010, vaccination against measles was only obligatory for children in 8 of the 29 (Haverkate et al. 2012). Within the 21 remaining countries, vaccination was recommended but voluntary. The debate about which of the two positions, voluntary or compulsory vaccination, is better from an ethical point of view, remains open (Moran et al. 2008; Schröder-Bäck et al. 2009).

Spain is one of the European countries where measles has reappeared. The first childhood immunization schedule (CIS) was introduced in Spain in 1975. In 1978, Spain began to vaccinate against measles (one dose at 15 months) which beginning in 1981 was administered as a measles-mumps-rubella (MMR) vaccine. Starting in 1990, a second dose at 11 years of age was introduced. In 2004, the age at which the second dose was administered was revised to 8 years of age. As a result, the illness almost disappeared over the course of a 20-year period: 220,096 cases in 1986, but only 17 cases in 2005. However, since that time, cases have increased, with periodic local outbreaks: 2006 (349 cases), 2007 (260 cases), 2008 (305 cases), 2009 (43 cases), 2010 (285 cases) and 2011 (3507 cases) (WHO 2012). In 2011, an infected person died.

In contrast with countries such as the United States, Spain has made childhood vaccination voluntary and not a requirement for attending school (Colgrove 2006; Stadlin et al. 2012). However, the average vaccine coverage rates are high (>90 %) (Masa et al. 2010). This can be attributed largely to the public health system's primary care teams, distributed throughout the country and composed of family doctors, pediatricians and nurses. Even so, there are still places where coverage is less extensive, particularly in poor parts of large cities with low levels of socioeconomic development.

In Spain, health professionals document administration of childhood vaccines in handwriting in a paper booklet maintained by the parents. They also register this information in the child's medical record, which is commonly computer based. However, discrepancies can occur between the two vaccine registration systems.

4.9.2 Case Description

You are the chief public health officer in a province of Spain. One day, a pediatrician tells you about a 13-year-old who is suspected to have measles. The child and his family attended a wedding the week before. Within 10 days, six more people who also attended the wedding were diagnosed with measles and nine secondary cases are confirmed. Of the secondary cases, seven were thought to have been exposed at school and two were in the hospital emergency ward.

All cases occurred in a historic quarter of the city with a large degree of cultural, economic, religious, ethnic, and social diversity. This multicultural identity diverges from the relative homogeneity of the rest of the city.

The public primary school of the historic quarter is now the focal point of the outbreak. There are 216 students enrolled in the school. You order two initial public health measures outlined in the regional health ministry's Alert Protocol for Measles: (1) that a letter be sent to parents asking them to bring their child's vaccination booklet to the school, and (2) that a meeting be held with the parents to have health professionals inform them about the disease and the immunization process.

As a result of the letter, the parents of 137 children take the vaccine booklet to the school, which shows a low degree of measles vaccine coverage (60 %). Those children not immunized are then vaccinated with their parents' consent. However, the parents of 79 children fail to bring the vaccine booklet to the school.

In the parent meeting, some of the parents express their support for the anti-vaccination movement. They express sentiments such as "the disease is a natural process, so we prefer to organize measles parties;" "risk of measles is very low, but vaccines are toxic poisons;" "a lot of hidden complications of vaccines exist, for example, autism;" and "Big Pharma and politicians are looking out for profits, not for the welfare of our kids." They also allege, "vaccination is not obligatory in Spain, and we have a right to educate our children in accordance with our values." These remarks generated a heated dispute between parents for and against vaccination. The majority of parents seem misinformed about the risks and benefits of vaccination and do not even know the immunization status of their own children.

The next day, the measles outbreak at the school comes to the attention of the local and national media. Alarmist messages and negative stories about anti-vaccination groups grab headlines. There are stories that seem to blame the outbreak on the cultural diversity of the historic quarter. You worry that the negative media reports may stigmatize the people living in this quarter or, even more worrisome, blame specific religious or ethnic groups.

Therefore, you consider adopting additional public health measures such as maximizing surveillance in the city, controlling emergency rooms to decrease (or eliminate) transmission, and vaccinating health professionals and children under 6 months. You also consider having unvaccinated children stay home, but health authorities reject the idea, alleging it would violate the right to education. Little by little, a number of parents consent to having their children vaccinated, or the children are stricken and become immune.

Nevertheless, new cases linked to the school continue to occur. In the regional health ministry, attention is turned to the possibility of requiring vaccination via a court order, citing a fundamental law that enables such exceptional actions in public health emergencies.

Finally, a request is put to the judge to authorize the enforced vaccination of 35 children. He does and you inform the parents. Two nurses, accompanied by a police officer, visit the houses one by one. The majority of the parents give consent to the vaccination. Ten days later, only nine children remain unvaccinated as a result of the refusal of their parents. You inform the judge that the number is so low that the situation of special risk generated has now been overcome. You suspend compulsory vaccinations.

Since the first case was diagnosed, 10 months have elapsed. A total of 308 cases have been confirmed, 96 in minors younger than 1 year old. And 71 patients required hospitalisation (23 %), including five adults.

4.9.3 Discussion Questions

1. What are the values, ethical principles, and rights that come into conflict in this case? If it is not possible to respect all of them, how should they be prioritized?
2. Is the decision to allow unvaccinated children to attend the school justified?
3. Think of a solution that adequately balances the freedom of choice of parents who are against vaccination with the protection of the health of a community where vaccination is not compulsory.
4. Was there sufficient epidemiological risk to justify the court order? Were there other possible solutions? Once the judicial measure had been adopted, why was it not pursued to its conclusion? Does the argument to suspend administering vaccines provide sufficient grounds for this decision?
5. Once the outbreak has subsided, what measures should be introduced to avoid further outbreaks? If the vaccination rate in the country later falls and new outbreaks occur, should the government consider mandatory vaccination?

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References

Castillo-Solorzano, C.C., C. Ruiz-Matus, B. Flannery, C. Marsigli, G. Tambini, and J.K. Andrus. 2011. The Americas: Paving the road toward global measles eradication. *Journal of Infectious Diseases* 204(suppl 1): S270–S278.

Colgrove, J. 2006. *State of immunity: The politics of vaccination in twentieth-century America*. Berkeley: University of California.

Flaherty, D.K. 2011. The vaccine-autism connection: A public health crisis caused by unethical medical practices and fraudulent science. *The Annals of Pharmacotherapy* 45(10): 1302–1304.

Haverkate, M., F. D'Ancona, C. Giambi, K. Johansen, P.L. Lopalco, and V. Cozza, et al. 2012. Mandatory and recommended vaccination in the EU, Iceland and Norway: Results of the VENICE 2010 survey on the ways of implementing national vaccination programmes. *Euro Surveillance* 17(22): pii: 20183. http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=20183. Accessed 10 June 2015.

Kata, A. 2010. A postmodern Pandora's box: Anti-vaccination misinformation on the internet. *Vaccine* 28(7): 1709–1716.

Masa, J., T. Castellanos, and M. Terrés. 2010. *Annual report of the Spanish plan for the eradication of measles and rubella–2010.* Working Party of the Spanish Plan for the Eradication of Measles and Rubella of the National Center of Epidemiology – Carlos III Institute of Health. http://www.isciii.es/ISCIII/es/contenidos/fd-servicios-cientifico-tecnicos/fd-vigilancias-alertas/fd-enfermedades/fd-enfermedades-prevenibles-vacunacion/Informe-Anual-Plan-Eliminacion-del- Sarampion-Rubeola-y-Sindrome-de-Rubeola-Congenita-Espana-2010.pdf. Accessed 10 June 2015.

Moran, N.E., S. Gainotti, and C. Petrini. 2008. From compulsory to voluntary immunisation: Italy's national vaccination plan (2005–2007) and the ethical and organisational challenges facing public health policy-makers across Europe. *Journal of Medical Ethics* 34(9): 669–674.
Muscat, M. 2011. Who gets measles in Europe? *The Journal of Infectious Diseases* 204(suppl 1): S353–S365.
Muscat, M., H. Bang, J. Wohlfahrt, S. Glismann, K. Mølbak, and EUVAC.NET Group. 2009. Measles in Europe: An epidemiological assessment. *Lancet* 373(9661): 383–389.
Schröder-Bäck, P., H. Brand, I. Escamilla, J.K. Davies, C. Hall, K. Hickey, et al. 2009. Ethical evaluation of compulsory measles immunisation as a benchmark for good health management in the European Union. *Central European Journal of Public Health* 17(4): 183–186.
Stadlin, S., R.A. Bednarczyk, and S.B. Omer. 2012. Medical exemptions to school immunization requirements in the United States—Association of state policies with medical exemption rates (2004–2011). *The Journal of Infectious Diseases* 206(7): 989–992.
World Health Organization (WHO). 2005. *Eliminating measles and rubella and preventing congenital rubella infection: WHO European Region Strategic Plan 2005–2010.* http://www.euro.who.int/__data/assets/pdf_file/0008/79028/E87772.pdf. Accessed 10 June 2015.
World Health Organization (WHO). 2010a. Proceedings of the global technical consultation to assess the feasibility of measles eradication, 28–30 July 2010. *The Journal of Infectious Diseases* 204(suppl 1): S4–S13. doi:10.1093/infdis/jir100.
World Health Organization (WHO). 2010b. *Resolution: Renewed commitment to elimination of measles and rubella and prevention of congenital rubella syndrome by 2015 and sustained support for poliofree status in the WHO European Region.* Regional Committee for Europe (EUR/RC60/R12). http://www.euro.who.int/__data/assets/pdf_file/0016/122236/RC60_eRes12.pdf. Accessed 10 June 2015.
World Health Organization (WHO). 2011. Increased transmission and outbreaks of measles, European region, 2011. *Weekly Epidemiological Record* 86(49): 557–564.
World Health Organization (WHO). 2012. *Centralized information system for infectious diseases (CISID): Measles.* Geneva: World Health Organization. http://data.euro.who.int/cisid. Accessed 10 June 2015.

4.10 Case 2: Public Health Approaches to Preventing Mother-to-Child HIV Transmission

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4.10.1 Background

The pursuit of global public health takes place in an unjust world, demanding that its practitioners judge when and to what extent to compromise their ideals and standards in order to remain effective. (Wikler and Cash 2009)

Mother-to-child transmission (MTCT)—also known as vertical transmission—is the primary cause of HIV infection in children under 10 years of age (Interagency Coalition on AIDS and Development 2011). Each year, more than 600,000 infants become infected with HIV from prenatal transmission during pregnancy, labor and delivery, or breastfeeding, primarily in under-resourced countries (Centers for Disease Control and Prevention 2012; Interagency Coalition on AIDS and Development 2011; Mnyani and McIntyre 2009).

For women who are HIV-negative, breastfeeding is the preferred child survival strategy. It is linked to a lower risk of various health problems for babies, including a reduction in the risk of death from diarrhea and malnutrition (World Health Organization 2007; O'Reilly et al. 2012). However, the risk of an HIV-positive woman transmitting the virus to her baby in the absence of any intervention ranges from 15 to 45 % (De Cock et al. 2000; World Health Organization 2015). Avoidance of breastfeeding (use of replacement feeding) reduces the risk of neonatal transmission to 20 % (Interagency Coalition on AIDS and Development 2011). Modified feeding, also known as mixed feeding (liquids or solids), results in a risk of transmission of about 30–35 % (Coutsoudis et al. 1999). The safety of replacing breastfeeding depends on access to clean water, a reliable supply of formula, and availability of instruction. Thus, use of mixed feeding techniques can be a challenge in many middle- or low-income countries (World Health Organization 2007; O'Reilly et al. 2012).

To help reduce the risk of babies becoming infected with HIV and to ensure quality services across the different levels of the health system, the World Health Organization (WHO) released revised guidelines in 2010 for use by managers of national HIV and AIDS programmers, as well as local managers and health care providers. The guidelines emphasize treatment for pregnant, HIV-infected women. Those with stage 3 or stage 4 disease (CD4 count $\leq$350 cells/μL) require lifelong three-drug antiretroviral therapy (ART) to treat their own HIV infections and for prevention of mother-to-child transmission of HIV (PMTCT). For women with less-advanced disease, WHO recommends a country- or program-level choice between Option A (maternal zidovudine during pregnancy and infant nevirapine [NVP] throughout breastfeeding), and Option B (maternal three-drug ART regimens throughout pregnancy and breastfeeding) (WHO 2010). Mutations of the virus can occur when the required course of treatment is not followed (Interagency Coalition on AIDS and Development 2011).

In many countries, social stigma, fear of the risk of discrimination, rejection, and violence can thwart a woman's intention to have an HIV test, take antiretroviral drugs, or substitute breast milk (Interagency Coalition on AIDS and Development 2011). Such obstacles arise in part from traditional beliefs and values and from unfamiliarity with the practice of biomedicine. In some cultures, a woman is viewed as responsible for her own HIV infection and that of her child, and she may suffer emotional or physical abuse at the hands of her family if her HIV status is discovered.

However, it can be important for her family to be aware of her HIV status, as they are often the ones who advise her on child feeding practices. Dealing with a woman's fear of being exposed as an HIV-positive mother is a challenge inherent in programs that focus on PMTCT.

4.10.2 Case Description

In a sub-Saharan African country, Dr. Charles directs a rural health clinic that an international organization funds. Funding requires the clinic to follow new WHO guidelines for the PMTCT. The guidelines specifically recommend using antiretroviral drugs throughout the breastfeeding period by HIV-positive women (WHO 2010). The district health office is also requiring Dr. Charles to develop guidance for his clinical staff on how to carry out the guidelines in a way that takes the values and beliefs of the community into account. Implementing the guidelines poses a major challenge for Dr. Charles because of the country's weak health infrastructure, the small number of paid staff in his clinic, and an inadequate facility with limited general supplies. However, his facility boasts a lab, and he has received some funding to support the PMTCT program.

Recently, a woman in labor came to the clinic and told Dr. Charles she was HIV positive. She wanted to know how she could breastfeed without awakening suspicions of her HIV status. She was worried that if neighbors or family found out, her husband would abandon her, and she would have to support herself and the child in a hostile environment.

4.10.3 Discussion Questions

1. How should this patient's plight influence Dr. Charles as he helps his clinic carry out the WHO guidelines? From a public health perspective, what conflicts does Dr. Charles have in meeting his patient's needs?
2. Who are the stakeholders Dr. Charles should consider as he develops his guidance and what information does he need to ensure success in reducing mother-to-child transmission of HIV in this community?
3. What procedures can he put in place to decrease the risk of HIV-positive women being stigmatized by their partners, family, or community?
4. How should the infant's well-being be balanced with maintaining the mother's health, social welfare, and survival?
5. To what extent should Dr. Charles consider the culture of his community in which family decision making and traditions about infant feeding often hamper mothers' efforts to decrease the risk for HIV transmission? How can public health programs build flexibility that anticipates cultural diversity in beliefs, values, and practice?
6. Instead of just focusing on his patients, should Dr. Charles consider holding structured conversations with people in the community to influence social norms or with village elders as a way to influence social norms counterproductive to program aims?

References

Centers for Disease Control and Prevention. 2012. *HIV for women.* http://www.cdc.gov/HIV/risk/gender/women/facts/index.html. Accessed 23 May 2013.

Coutsoudis, A., K. Pillay, E. Spooner, L. Kuhn, and H.M. Coovadia. 1999. Influence of infant-feeding patterns on early mother-to-child transmission of HIV-1 in Durban, South-Africa: A prospective cohort study. *Lancet* 354(9177): 471–476.

De Cock, K.M., M. Fowler, E. Mercier, et al. 2000. Prevention of mother-to-child HIV transmission in resource-poor countries: Translating research into policy and practice. *JAMA* 283(9): 1175–1182. doi:10.1001/jama.283.9.1175.

Interagency Coalition on AIDS and Development. 2011. *HIV/AIDS: Mother-to-child transmission.* http://www.icad-cisd.com/. Accessed 23 May 2013.

Mnyani, C., and J. McIntyre. 2009. Preventing mother-to-child transmission of HIV. *BJOG: An International Journal of Obstetrics & Gynaecology* 116(suppl 1): 71–76.

O'Reilly, C.E., P. Jaron, B. Ochieng, et al. 2012. Risk factors for death among children less than 5 years old hospitalized with diarrhea in rural western Kenya, 2005–2007: A cohort study. *PLoS Medicine* 9(7): e1001256. doi:10.1371/journal.pmed.1001256.

Wikler, D., and R. Cash. 2009. Ethical issues. In *Global public health: A new era*, ed. R. Beaglehole and R. Bonita, 249–266. Oxford: Oxford University Press.

World Health Organization (WHO). 2007. *HIV transmission through breastfeeding: A review of available evidence.* http://whqlibdoc.who.int/publications/2008/9789241596596_eng.pdf. Accessed 1 May 2013.

World Health Organization (WHO). 2010. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants.* http://www.who.int/hiv/pub/mtct/guidelines/en/. Accessed 1 May 2013.

World Health Organization (WHO). 2015. *Mother-to-child transmission of HIV.* http://www.who.int/hiv/topics/mtct/en/. Accessed 1 June 2015.

4.11 Case 3: Newborn Bloodspot Screening: Personal Choice or Public Health Necessity? Storage and Ownership of Newborn Bloodspots

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4.11.1 Background

Newborn bloodspot screening (NBS) is the process in which a small blood sample is collected from the heel of a newborn, sent to a laboratory, and tested for serious and life-limiting conditions. If diseases are detected in the newborn period, treatment can begin immediately. NBS is conducted on almost 100 % of the newborn population in North America, roughly four million infants per year in the United States (Botkin et al. 2012). Screening panels have steadily increased the number of conditions tested, with upward of 40 conditions included in some NBS programs. This momentum to include more conditions in screening panels reflects a transition away from an 'emergency' model to a 'public health service' model. In the emergency model, testing identifies conditions amenable to treatment or associated with catastrophic morbidity or mortality. In contrast, a key goal of the public health service model is to inform decision making or avoid a "diagnostic odyssey" (Bailey et al. 2006; Buchbinder and Timmermans 2011; Metcalfe et al. 2012). Advances in newborn screening have increased our ability to detect previously unidentifiable conditions. However, they have also raised a number of ethical challenges about how to best use the information. For example, testing can now reveal someone's carrier status (i.e., the person carries a recessive copy of a genetic disorder without being affected by the condition). Knowing a child's carrier status can inform future reproductive decision making but may induce anxiety, lead to potential stigma, or reveal non-paternity (Hayeems et al. 2008).

Newborn screening is a routine practice in many states. In the U.S. state of Nebraska, for example, screening is mandatory without exception (Schweers 2012; Foral 2006). In other U.S. states, screening proceeds on an opt-out basis, although studies indicate that often parents are not afforded the opportunity to consent or are poorly informed about the opt-out option (Botkin et al. 2012). This may even be the case where screening proceeds in an ostensibly informed choice manner, such as in the United Kingdom (Nicholls 2012; Nicholls and Southern 2012).

Dried bloodspot samples are often stored for a number of years after collection, but the length of storage varies by jurisdiction (Botkin et al. 2012). Samples are retained for various reasons including repeat testing, quality control of testing procedures, or as part of diagnosis. In addition, samples also may be used (anonymously) for external quality assurance and research. While there is no consensus, a recent expert panel recommended a minimum storage period of about 3 months to allow for quality assurance, and indefinite storage when initial positive (i.e., disease suspected) results are confirmed by diagnostic testing (Botkin et al. 2012). In five U.S. states, a parent has the legal right to request destruction or release of dried bloodspot samples, and in three states children may do so when they reach the age of majority (Lewis

et al. 2011). A number of other jurisdictions have followed suit with similar procedures (Newborn Screening Ontario 2011). In most cases, release or destruction of the bloodspot requires a signed formal request by a parent or legal guardian.

Research to date has provided important findings for both clinical decision making and public health. For example, studies exploring childhood leukemia have used bloodspots to identify whether genetic changes are present at birth, or have accumulated over time, helping to clarify how the disease is caused. Others have considered the effects of public health policies, such as the removal of perfluorinated compounds, and examined the levels of these in bloodspot samples, noting significant declines in analyte levels following the phasing out of these compounds (Spliethoff et al. 2008). As such, bloodspots may provide a useful resource for evaluating public health policy. Bloodspot samples may also be requested by the coroner's office or be used in forensic investigations as was proposed, for example, in the Netherlands following an explosion at a fireworks factory (Couzin-Frankel 2009; Douglas et al. 2012).

However, there has been a great deal of media discussion regarding the retention, storage, and use of dried bloodspots due to public concerns about privacy (Couzin-Frankel 2009; Muchamore et al. 2006; Bombard et al. 2012). In particular, there has been debate regarding the secondary use of stored bloodspots for research, which are seen as having tremendous research value (Tarini 2011). This has culminated in several lawsuits in the United States and Canada (Lewis et al. 2012; Armstrong 2010) that have led to changes in storage policy and the destruction of millions of dried bloodspot samples (Lewis et al. 2012).

4.11.2 Case Description

As manager of a newborn screening program, you are responsible for the daily operations of the program, as well as risk and resource management, program evaluation, and quality improvement initiatives. Your program screens approximately 150,000 newborns annually for 28 conditions. Each year, on average, 140 babies are identified as affected by at least one of the screened conditions.

Your program publishes a leaflet and hosts a website that provides information for parents regarding the screening process, the conditions for which screening is conducted, and about storage. Your jurisdiction's regulations recommend that bloodspot samples be stored for a minimum of 5 years. Parents have the legal right to request destruction or release of a bloodspot sample at any time. To do so, the parents or legal guardian must complete a request form.

While parents are informed of the screening process and retention of bloodspots, consent is not required, and screening proceeds on an 'opt-out' basis (i.e., screening proceeds unless parents explicitly object). There is no distinction between decisions for screening and decisions regarding retention of bloodspots.

The recent debate regarding the secondary use of stored bloodspots for research has increased researcher awareness of bloodspots as a resource and has put increased pressure on your office to facilitate research requests. At the same time, you have

also received political pressure from the health ministry to review storage and consent policy due to public concerns about privacy.

In light of increasing media and researcher interest and political pressure, the health ministry has asked the standing advisory committee on newborn screening to convene a working group to review your jurisdictions' policy on the retention of newborn bloodspots and the information provided to parents. You have been charged with advising the committee regarding potential policy changes and the potential impacts of these on the screening program.

You are aware of the potential conflict between public health benefits and parental consent to the secondary use of bloodspots for research. However, you are concerned that providing too much information or raising concerns with parents may decrease uptake of what is an important population screening program.

4.11.3 Discussion Questions

1. Newborn bloodspot screening is both a public health program and a tool for individual clinical care. How should the public health gains from newborn screening weigh against individual privacy concerns?
2. Given expressed concerns, how should participation in newborn screening be managed? Should the current opt-out policy be retained or would an informed consent model be ethically more justifiable? Should screening be distinguished from secondary use? If so, how should these two elements be handled?
3. To what extent, if any, should the screening program attempt to persuade parents to withdraw their requests for return or destruction of bloodspots?
4. Studies indicate that anonymized research data might be de-anonymised via surname inference using genealogy databases (Gymrek et al. 2013) or based on date of birth, gender, and 5-digit ZIP code (Sweeney et al. 2013). Should parents have the right to consent or opt out of studies even in cases where only anonymised data is used, and which may provide improvements to population health?
5. Should residual dried bloodspots ever be made available to researchers? How should clinically actionable results be dealt with?
6. One option is the indefinite storage of residual bloodspots. Is this permissible, and if so, should the consent of the child be sought when they reach the age of majority?

References

Armstrong, J. 2010. Storage of newborns' blood samples raises privacy concerns. *The Globe and Mail*, May 11. http://www.theglobeandmail.com/news/british-columbia/storage-of-newborns-blood-samples-raises-privacy-concerns/article4318768/. Accessed 30 May 2013.

Bailey Jr., D.B., L.M. Beskow, A.M. Davis, and D. Skinner. 2006. Changing perspectives on the benefits of newborn screening. *Mental Retardation and Developmental Disabilities Research Reviews* 12(4): 270–279. doi:10.1002/mrdd.20119.

Bombard, Y., F.A. Miller, R.S. Hayeems, et al. 2012. Citizens' values regarding research with stored samples from newborn screening in Canada. *Pediatrics* 129: 239–247. doi:10.1542/peds.2011-2572.

Botkin, J.R., A.J. Goldenberg, E. Rothwell, et al. 2012. Retention and research use of residual newborn screening bloodspots. *Pediatrics* 131(1): 1–8. doi:10.1542/peds.2012-0852.

Buchbinder, M., and S. Timmermans. 2011. Newborn screening and maternal diagnosis: Rethinking family benefi t. *Social Science & Medicine* 73(7): 1014–1018. doi:10.1016/j.socscimed.2011.06.062.

Couzin-Frankel, J. 2009. Newborn blood collections. Science gold mine, ethical minefield. *Science* 324(5924): 166–168.

Douglas, C., C. van El, M. Radstake, S. van Teeffelen, and M.C. Cornel. 2012. The politics of representation in the governance of emergent 'secondary use' biobanks: The case of dried blood spot cards in the Netherlands. *Studies in Ethics, Law, and Technology* 6(1): Article 4. doi:10.1515/1941-6008.1178.

Foral, F.E. 2006. Necessity's sharp pinch: Parental and states' rights in conflict in an era of newborn genetic screening. *Journal of Health & Biomedical Law* 11(1): 109–128.

Gymrek, M., A.L. McGuire, D. Golan, and Y. Erlich. 2013. Identifying personal genomes by surname inference. *Science* 339(6117): 321–324. doi:10.1126/science.1229566.

Hayeems, R.Z., J.P. Bytautas, and F.A. Miller. 2008. A systematic review of the effects of disclosing carrier results generated through newborn screening. *Journal of Genetic Counseling* 17(6): 538–549. doi:10.1007/s10897-008-9180-1.

Lewis, M.H., A. Goldenberg, R. Anderson, E. Rothwell, and J. Botkin. 2011. State laws regarding the retention and use of residual newborn screening blood samples. *Pediatrics* 127(4): 703–712. doi:10.1542/peds.2010-1468.

Lewis, M.H., M.E. Scheurer, R.C. Green, and A.L. McGuire. 2012. Research results: Preserving newborn blood samples. *Science Translational Medicine* 4(159): 1–3.

Metcalfe, S.A., A.D. Archibald, and A.L. Atkinson, et al. 2012. *Conflicting views on newborn and infant genetic screening: Perspectives of relatives of children with genetic conditions causing developmental delay and parents of healthy children.* Paper presented at the 62nd annual meeting of the American Society of Human Genetics, San Francisco, CA, 6–10 November.

Muchamore, I., L. Morphett, and K. Barlow-Stewart. 2006. Exploring existing and deliberated community perspectives of newborn screening: Informing the development of state and national policy standards in newborn screening and the use of dried blood spots. *Australia and New Zealand Health Policy* 3: 14. doi:10.1186/1743-8462-3-14.

Newborn Screening Ontario. 2011. *Storage and secondary use of the newborn screening samples.* Ottawa. http://www.newbornscreening.on.ca/data/1/rec_docs/434_Storage_and_Secondary_Use_of_the_Newborn_Screening_Samples.pdf. Accessed 28 Jan 2014.

Nicholls, S.G. 2012. Proceduralisation, choice and parental reflections on decisions to accept newborn bloodspot screening. *Journal of Medical Ethics* 38: 299–303. doi:10.1136/medethics-2011–100040.

Nicholls, S.G., and K.W. Southern. 2012. Informed choice for newborn blood spot screening in the United Kingdom: A survey of parental perceptions. *Pediatrics* 130(6): e1527–e1533. doi:10.1542/peds.2012-1479.

Schweers, R.L. 2012. Newborn screening programs: How do we best protect privacy rights while ensuring optimal newborn health? *DePaul L Rev* 61: 869.

Spliethoff, H.M., L. Tao, S.M. Shaver, et al. 2008. Use of newborn screening program blood spots for exposure assessment: Declining levels of perfluorinated compounds in New York State infants. *Environmental Science & Technology* 42(14): 5361–5367.

Sweeney, L., A. Abu, and J. Winn. 2013. *Identifying participants in the personal genome project by name.* Cambridge, MA: Harvard University Data Privacy Lab. White Paper 1021–1. http://privacytools.seas.harvard.edu/files/privacytools/fi les/1021-1.pdf. Accessed 30 May 2013.

Tarini, B.A. 2011. Storage and use of residual newborn screening blood spots: A public policy emergency. *Genetics in Medicine* 13(7): 619–620. doi:10.1097/GIM.0b013e31822176df.

4.12 Case 4: Decoding Public Health Ethics and Inequity in India: A Conditional Cash Incentive Scheme—Janani Suraksha Yojana

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4.12.1 Background

The domestic sphere of home and family defines the lives of most women in India, where they assume the role of caregiver, either as wife or mother. Overall, age and sex govern the household's hierarchy of authority, older over younger, men over women. Women, especially those living in northern India, experience decreased autonomy and increased inequalities in all areas of life (Iyengar et al. 2009; Bloom et al. 2001). Limited autonomy harms women's maternal health outcomes, restricting their ability to choose safe childbirth options. In India, most births still occur in the home; less than 41 % occur in an institutional setting (International Institute for Population Sciences 2007).

Worldwide, more than half a million women die each year from complications during pregnancy and childbirth (UNICEF 2009). About 99 % of these deaths occur in developing countries. Based on maternal mortality trends from 1990 to 2008, developing countries, especially India, contribute about 18 % of the global burden of maternal deaths (Dikid et al. 2013). Data during 2007 through 2009 indicated that India's maternal mortality ratio (MMR) was 212 per 100,000 live births (Registrar General of India 2011). Regional differences in MMR are found in India; during 2007 through 2009 the MMR in northern states was 308/100,000 compared with 207/100,000 in the southern states.

India has had a long history of redistributive poverty-reduction programs, but few programs provide direct cash assistance to the needy (Mehrotra 2010). Cash incentive programs started in the 1990s predominantly in Latin America where their success led to adoption in other parts of the world (Powell-Jackson et al. 2009b). These programs vary in size and scope; examples include programs that address vaccinations, education, health care, safe childbirth, sterilization, and poverty. An example from an Asian country is the Safe Delivery Incentives Programme (SDIP), which was started in

2005 in Nepal with funds from the U.K. Department of International Development and the Nepalese government (Powell-Jackson et al. 2009a; Karki 2012). The program provided cash incentives to women who gave birth in health facilities and to health providers for each attended delivery (either in the woman's home or in a facility). The program implementers or administrators expected that the cash incentive would reduce transportation barriers and delays in maternal care seeking (Bhandari and Dangal 2012). The program was most effective in changing health care-seeking behavior wherever women's groups highlighted the importance of effective communication of the policy to the public (Powell-Jackson et al. 2008). Women exposed to the program were 24 % more likely to deliver in government health institutions, 5 % less likely to deliver at home, and 13 % more likely to have their delivery attended by a skilled health worker. Deliveries in government health institutions went from 34 % in the first year (2005/2006) to 59 % in the third year (2007/2008). Overall, the program was well received, however certain aspects of the policy were not accepted, including a condition that limited receipt of the cash incentive to women who had no more than two living children (Powell-Jackson et al. 2008).

India's conditional cash transfer program, Janani Suraksha Yojana (JSY), is one of the largest programs of its kind in the world (Lim et al. 2010). JSY is funded through the central government, provides welfare to women living in indigent families, and includes efforts to empower women to choose institutional childbirth rather than home delivery.

JSY represents a novel and useful way to ensure the social welfare of women by integrating cash assistance with childbirth delivery and post delivery care. The program focuses on poor pregnant woman, especially those living in states with high MMRs and low institutional delivery rates. These low-performing states include Uttar Pradesh, Uttaranchal, Bihar, Jharkhand, Madhya Pradesh, Chhattisgarh, Assam, Rajasthan, Orissa, and Jammu and Kashmir (Tiwari 2013). An important component of this program is its focus on monitoring, evaluating, and providing, health care for the mother and her baby (Lim et al. 2010). District-level household surveys have documented a decline in the proportion of home deliveries, which dropped from 59 % in the 2002–2004 survey (International Institute for Population Sciences 2006) to 52 % in the 2007–2008 survey (International Institute for Population Sciences 2010).

Despite indicators of success, the JSY program has raised a number of concerns. One of the aims of JSY is equity in addition to coverage; the JSY program does not include private health care providers. The increased deliveries (from 35 % to 65 %) in public health care facilities may raise issues in the quality and standards of health care (MacDonald 2011). Another concern is that the lack of comprehensive emergency obstetric care at many institutions compromises the safety of institutional deliveries (International Institute for Population Sciences 2010). A final concern is that socioeconomic status, caste, and education create large inequities in access to the program's cash incentives, while women who do gain access lack financial control over the cash incentives (Gopichandran and Chetlapalli 2012).

4.12.2 Case Description

A 19-year-old woman from a poor area in India is pregnant for the first time and only weeks from her delivery date. Wearing a long pardah to cover the lower half of her face and traditional maang tikka jewelry on her forehead to indicate married status, her attire reflects the traditional values embedded in her culture. She wants to deliver her baby in her home village, which is an overnight's journey away. But her husband and in-laws have other ideas. They have just learned of a government program that provides a cash payment of 1000 rupees to women who opt for institutional delivery over home delivery. Her mother-in-law insists that the delivery take place in their district institution. The woman's parents, believing the in-laws to be driven purely by greed, support their daughter. With encouragement from her parents, the woman disobeys her husband and in-laws to travel to her parent's home, but goes into labor on the road and loses her child due to complications in the delivery. The young woman not only is disconsolate over the loss of her child, she must now face the wrath of her husband and in-laws.

This is a poignant case, but only one in a dossier full of similar cases that you, as the state director for the maternal cash incentive program, have read that involve clashes between traditional ways and the incentive program. As a result, you have decided to convene an expert panel to consider recommendations to smooth not only the cultural friction the program is causing, but also the program's impact on the quality and safety of care, as well as access to it.

4.12.3 Discussion Questions

1. Who are the main stakeholders in the case of the 19-year-old woman and what values and cultural perspectives does each stakeholder bring to this situation?
2. How should you consider the issues about this and similar cases when deciding whether to revise the cash incentive program?
3. What are the pros and cons of cash incentive programs from a public health perspective?
4. What role should government play in improving the public's health?
5. In the context of inequities based on socioeconomic status, caste, and education, to what extent should you attempt to ensure that a woman's autonomy is not violated? Should the same notion of autonomy be applied in India or other unique contexts as prevails in European and North American countries?
6. Due to a financial downturn, the state government is thinking about eliminating the maternal cash benefit program. How can an ethical analysis assist in making this decision? What factors should be considered as part of this ethical analysis?

References

Bhandari, T.R., and G. Dangal. 2012. Maternal mortality: Paradigm shift in Nepal. *Nepal Journal of Obstetrics and Gynecology* 7(2): 3–8.

Bloom, S.S., D. Wypij, and M. Das Gupta. 2001. Dimensions of women's autonomy and the influence on maternal health care utilization in a north Indian city. *Demography* 38: 67–78.

Dikid, T., M. Gupta, M. Kaur, S. Goel, A.K. Aggarwal, and J. Caravotta. 2013. Maternal and perinatal death inquiry and response project implementation review in India. *Journal of Obstetrics and Gynaecology of India* 63(2): 101–107.

Gopichandran, V., and S.K. Chetlapalli. 2012. Conditional cash transfer to promote institutional deliveries in India: Toward a sustainable ethical model to achieve MDG 5A. *Public Health Ethics* 5(2): 173–180.

International Institute for Population Sciences (IIPS). 2006. *District Level Household Survey (DLHS-2), 2002–04: India.* Mumbai: IIPS. http://www.rchiips.org/PRCH-2.html. Accessed 29 May 2013.

International Institute for Population Sciences. 2010. *District Level Household Survey (DLHS-3), 2007–08: India.* Mumbai: IIPS. http://www.rchiips.org/pdf/INDIA_REPORT_DLHS-3.pdf. Accessed 29 May 2013.

International Institute for Population Sciences and Macro International. 2007. *National Level Household Survey (NFHS-3), 2005–06: India: Volume I.* Mumbai: IIPS. http://www.rchiips.org/nfhs/nfhs3_national_report.shtml. Accessed 29 May 2013.

Iyengar, S.D., K. Iyengar, and V. Gupta. 2009. Maternal health: A case study of Rajasthan. *Journal of Health, Population, and Nutrition* 27(2): 271–292.

Karki, A. 2012. *Safe delivery incentive program under maternal health financing policy of Nepal: A case of Kailali district in Nepal.* Dhaka: North South University. Accessed 29 May 2013.

Lim, S.S., L. Dandona, J.A. Hoisington, S.L. James, M.C. Hogan, and E. Gakidou. 2010. India's Janani Suraksha Yojana, a conditional cash transfer programme to increase births in health facilities: An impact evaluation. *Lancet* 375(9730): 2009–2023.

MacDonald, R. 2011. Janani Suraksha Yojana—The Indian way of improving maternal and child health. *PLOS Medicine Community Blog.* http://blogs.plos.org/speakingofmedicine/2011/12/19/janani-suraksha-yojana-%E2%80%94-the-indian-way-of-improving-maternal-and-child-health/. Accessed 29 May 2013.

Mehrotra, S. 2010. *Introducing conditional cash transfers in India: A proposal for five CCTs.* Institute of Applied Manpower Research, Planning Commission. http://www.google.com/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=1&ved=0CCYQFjAA&url=http%3A%2F%2Fwww.ids.ac.uk%2Ffiles%2Fdmfile%2FConditionalCashTransfersforDevChange2.doc&ei=MBrpUpbqN5C_sQTo74G4Bg&usg=AFQjCNHUgH8o22hjaLX1SNVgsjwK8Ww_YQ&bvm=bv.60157871,d.cWc. Accessed 29 May 2013.

Powell-Jackson, T., B.D. Neupane, S. Tiwari, J. Morrison, and A. Costello. 2008. *Evaluation of the safe delivery incentive programme: Final report of the evaluation.* Nepal: Support to Safe Motherhood Programme. http://s3.amazonaws.com/zanran_storage/www.safemotherhood.org.np/ContentPages/2469459188.pdf. Access 29 May 2013.

Powell-Jackson, T., J. Morrison, S. Tiwari, B.D. Neupane, and A.M. Costello. 2009a. The experiences of districts in implementing a national incentive programme to promote safe delivery in Nepal. *BMC Health Services Research* 9: 97. http://www.biomedcentral.com/content/pdf/1472-6963-9–97.pdf. Accessed 29 May 2013.

Powell-Jackson, T., B.D. Neupane, S. Tiwari, K. Tumbahangphe, D. Manandhar, and A.M. Costello. 2009b. The impact of Nepal's national incentive programme to promote safe delivery in the district of Makwanpur. *Advances in Health Economics and Health Services Research* 21: 221–249.

Registrar General of India. 2011. *Maternal and child mortality and total fertility rates: Sample registration system.* New Delhi: Registrar General of India. http://censusindia.gov.in/vital_statistics/SRS_Bulletins/MMR_release_070711.pdf. Accessed 29 May 2013.

Tiwari, D. 2013. *Role of national rural health mission in promoting institutional delivery services in rural Uttar Pradesh, India: An assessment of Janani Suraksha Yojana.* Paper presented at the 2013 annual meeting of the Population Association of America, New Orleans, 10–13 April.
UNICEF. 2009. *The state of the world's children 2009: Maternal and newborn death.* http://www.unicef.org/sowc09/docs/SOWC09-FullReport-EN.pdf.

4.13 Case 5: HIV Criminalization and STD Prevention and Control

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4.13.1 Background

About 34.0 million people live with HIV worldwide, with 1.1 million residing in the United States (Centers for Disease Control and Prevention 2010). The lack of a cure, coupled with the ailment's debilitating and potentially fatal consequences, has prompted governments to enact structural interventions that, although well-intentioned, may be ineffective in preventing and controlling the spread of HIV.

HIV-specific criminal statutes are one example of a structural intervention used in at least 63 countries, including the United States. In the United States, the initial federal response to HIV included potential criminal prosecution for people aware of their HIV-positive status who knowingly engaged in sexual activity with the intent to expose others to HIV. Under the original text of the Ryan White Care Act of 1990, no federal grant would be issued to a state unless it had criminal laws under which to prosecute an HIV-infected person who knowingly engaged in sexual relations, donated blood (or semen or breast milk), or injected himself with a needle and provided the needle to another, with the intent to expose the other person to HIV (Public Law 101–381 1990). The Ryan White Care Act of 1990 became a template for many states, leading to the passage of laws that included a determination of guilt for HIV-infected individuals who engaged in sexual activity or shared drug paraphernalia. Consent was a defense so long as the uninfected person knew of the partner's HIV-positive status and provided informed consent before engaging in the activity (i.e., sexual or drug-related) (Public Law 101–381, 1990). Although the provision to award grants on the

condition of having an HIV-criminal law in place was repealed in 2000, more than 33 states currently have one or more HIV-specific criminal laws in effect.

While the merits of using criminal law to prevent HIV transmission remains questionable, there has not been enough thought given to the related effect of laws criminalizing commercial sex work that, coupled with HIV-criminalization laws, poses unique challenges for women and public health professionals. Together, these laws disproportionately affect women by virtue of their voluntary participation in—or coercion into—prostitution, and the harsher sentencing that may ensue upon conviction. In the state of Florida, for example, prostitutes who test positive for HIV before committing a crime have their sentence increased from a misdemeanor (serving a term of imprisonment not exceeding 1 year) to a felony (serving a term of imprisonment not exceeding 5 years) (Fl. Stat. Ann. § 796.08(4)(2010)). Notably, a person convicted of prostitution in Florida must undergo mandatory HIV testing. Consequently, the specter of criminal prosecution and up to 5 years imprisonment may deter many women from getting tested in the first place, increasing the risk of acquiring and transmitting the virus.

Globally, women are at heightened risk of contracting HIV because of social, economic, and cultural factors stemming from human rights violations, gender inequality, and inadequate forums to pursue legal redress (Murthy and Bhattacharya 2010). An estimated 60 % of people infected with HIV in sub-Saharan Africa are women; and females ages 15–24 years make up 75 % of those afflicted with the virus. Moreover, "male-to-female transmission during sex is about twice as likely to occur as female-to-male transmission, if no other sexually transmitted infections are present" (Joint United Nations Programme on HIV/AIDS [UNAIDS] 2004). For commercial sex workers, this disproportionate risk of exposure is exacerbated. Researchers have found that among female sex workers 15–49 years old, the prevalence of HIV infection is 13.5 times higher than the prevalence among the general population of women (Kerrigan et al. 2013).

Public health practitioners are faced with a dilemma of promoting HIV testing and simultaneously adhering to mandatory reporting requirements. All states in the United States have enacted laws or regulations requiring laboratory reporting of HIV infection, with 32 states (and the District of Columbia) also enacting laws requiring reporting of CD4 levels (white blood cells that protect against infection) and viral loads of people who test positive (Centers for Disease Control and Prevention 2013). Nonexistent or inadequate surveillance of commercial sex workers, however, may prevent researchers from understanding the evolving nature of HIV and the burden it poses on this particular population. For example, a recent study found that a common CD4 gene variant (i.e. alteration of the gene sequence) is associated with an increased risk of HIV-1 infection in Kenyan female commercial sex workers (Oyugi et al. 2009). The researchers suggest that the effect of this variant on the epidemic in Africa could be dramatic.

For many human rights activists, laws criminalizing sex work discriminate against women and deny them their right to work. For others, prostitution is inherently exploitative, with all commercial sex workers being victims who are denied legitimate (i.e., alternative) forms of employment. In most countries, however, the

law does not discriminate between these types of women or their reasons for engaging in commercial sex work, compelling many women to avoid HIV testing altogether (UNAIDS 2012a). By contrast, where voluntary counseling and testing have been extended to commercial sex workers, the results have been far more promising. A recent study found that voluntary counseling and treatment among a cohort of 421 commercial sex workers in Guinea resulted in 92 % of participants returning for their results (Aho et al. 2012).

The 35th anniversary of the international Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) affords an opportunity for governments to affirm that extending HIV services to commercial sex workers and promoting public health are not mutually exclusive endeavors. As the only treaty that rejects sex-discrimination in employment and in health care access, CEDAW helps women show the link between health and human rights, and particularly the right to health and employment. The CEDAW Committee, which oversees the treaty's execution, has advocated for the decriminalization of prostitution, in countries like China, where women are disproportionately prosecuted in lieu of the traffickers and pimps; and encourages governments to focus on rehabilitating and reintegrating women into society, enhancing opportunities, and providing support to ensure that their civil liberties are not violated (CEDAW 1981, Committee on the Elimination of Discrimination Against Women 2006). As of 2013, 187 countries are parties to CEDAW, but the United States has not ratified it (United Nations 2013).

4.13.2 Case Description

You are the sexually transmitted infections (STI) program manager of the Communicable Disease Control Unit in a public health department in a large city. A recent news story of an HIV-positive commercial sex worker has prompted public concern. While reviewing the county's HIV surveillance report for the last period of data collection, you note that the department does not conduct official surveillance of commercial sex workers. Studies have found that the HIV infection rate among female prostitutes has been as low as 12 % in Atlanta and as high as 57 % in northern New Jersey (Elifson et al. 1999). You are also aware of a UNAIDS report that found "where health and social services are provided and sex workers are actively engaged in efforts to provide universal access to HIV prevention, treatment, care and support, HIV incidence declines" (UNAIDS 2012b). Therefore, you are eager to start an intervention program that encourages commercial sex workers to undergo HIV testing. You recall that an intervention in a neighboring state used caseworkers to offer prostitutes testing for STIs, including HIV. However, a number of challenges abound.

Prostitution is illegal in your state, with penalties ranging from a Class A misdemeanor (punishable by up to a year in prison) for first-time offenders, to a Class 4 felony (punishable by 1–3 years in prison) for repeat offenders. Moreover, state law requires that health care providers report to the Department of Health the names of patients who test HIV-positive.

As an STI program manager, you are aware of the role of social determinants of health and the need to think broadly about possible interventions and collaborations with other agencies. You have been influenced by a study on 222 commercial sex workers from the Center for Impact Research (2002) that found the following:

- 72 % of young commercial sex workers had run away from home and were likely to have used drugs or alcohol growing up;
- 60 % reported domestic violence in the household;
- 25 % had completed a high school education or passed a general educational development (GED) test;
- More than 50 % grew up in a household in which prostitution took place;
- 87 % had someone suggest they engage in prostitution while they were growing up;
- 22 % reported they were HIV-positive;
- 21 % indicated being raped more than 10 times;
- 50 % of women worked on behalf of another person (i.e., pimp), with 75 % reporting they believed the other person would harm them if they discontinued their services;
- More than 90 % increased their drug or alcohol use after becoming commercial sex workers;
- Almost 75 % of them had been arrested at least once, with close to 50 % of them reporting that the arrest took place before age 18; and
- More than 50 % were homeless.

Your health department provides services related to homeless prevention and substance abuse treatment, yet eligibility is dependent on an ability to meet monetary obligations (rent, utilities, etc.) after the assistance has been granted based on current or anticipated income. It is unlikely that commercial sex work would satisfy this criterion.

You consider all of these issues as you think about how to begin an intervention program for commercial sex workers to encourage them to undergo HIV testing.

4.13.3 Discussion Questions

1. Who are the main public and private stakeholders in this case?
2. How should the criminal nature of commercial sex work influence the intervention you develop to encourage commercial sex workers to undergo HIV testing? Should your intervention also target other risk factors for illness, such as homelessness, unemployment, and substance abuse?
3. Are you obligated to seek help from law enforcement to carry out your intervention?
4. What standard should you use to evaluate your intervention's success? How would you treat empirical findings alongside issues of equity and discrimination?

5. Given the many social determinants implicated by prostitution and its attendant health effects, what other agencies should you collaborate with and what other services should you consider providing along with, or instead of, HIV testing?
6. Does the threat of prison ever get in the way of promoting healthy behaviors? If so, what criteria should be used to determine which activities and behaviors merit criminalization? Does reducing the number of women engaged in commercial sex work or their incidence of HIV—or both—satisfy these criteria?
7. Should the public health department conduct surveillance of the incidence of HIV among commercial sex workers? What challenges exist for the department in undertaking this task?
8. Do you think ratification of international laws like CEDAW can improve the health of commercial sex workers?

References

Aho, J., V.K. Nguyen, S.L. Diakité, A. Sow, A. Koushik, and S. Rashed. 2012. High acceptability of HIV voluntary counselling and testing among female sex workers: Impact of individual and social factors. *HIV Medicine* 13(3): 156–165.

Center for Impact Research. 2002. *Sisters speak out: The lives and needs of prostituted women in Chicago. A research study.* http://www.healthtrust.net/sites/default/files/publications/sisters-speakout.pdf. Accessed 1 June 2015.

Centers for Disease Control and Prevention. 2010. *HIV in the United States: At a glance.* http://www.cdc.gov/hiv/statistics/basics/ataglance.html. Accessed 29 May 2013.

Centers for Disease Control and Prevention. 2013. *State laboratory reporting laws: Viral load and CD4 requirements.* http://www.cdc.gov/hiv/law/states/laboratory.htm. Accessed 1 June 2015.

Committee on the Elimination of Discrimination Against Women. 2006. *Concluding comments of the committee on the elimination of discrimination against Women: China.* http://www.un.org/womenwatch/daw/cedaw/cedaw36/cc/CHINA_advance%20unedited.pdf. Accessed 1 June 2015

Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). 1981. *Sex role stereotyping and prejudice.* Article 5(a)-(b), Sept. 3, 1981, 1249 U.N.T.S. 13. http://www.un.org/womenwatch/daw/cedaw/cedaw.htm. Accessed 1 June 2015.

Elifson, K.W., J. Boles, W.W. Darrow, and C.E. Sterk. 1999. HIV seroprevalence and risk factors among clients of female and male prostitutes. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology* 20(2): 195–200.

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2004. *Report on the Global AIDS epidemic.* http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/unaidspublication/2004/GAR2004_en.pdf. Accessed 25 June 2015.

Joint United Nations Programme on HIV/AIDS. 2012a. *Criminalisation of HIV non-disclosure, exposure and transmission: Background and current landscape.* http://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/BackgroundCurrentLandscapeCriminalisationHIV_Final.pdf. Accessed 1 June 2015.

Joint United Nations Programme on HIV/AIDS. 2012b. *UNAIDS guidance note on HIV and sex work.* http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2009/JC2306_UNAIDS-guidance-note-HIV-sex-work_en.pdf. Accessed 1 June 2015.

Kerrigan, D., A. Wirtz, S. Baral, et al. 2013. *The global HIV epidemics among sex workers.* Washington, DC: World Bank. http://www.worldbank.org/content/dam/Worldbank/document/GlobalHIVEpidemicsAmongSexWorkers.pdf. Accessed 1 June 2015.

Murthy, P., and D. Bhattacharya. 2010. Human rights and women's health. In *Rights-based approaches to public health*, ed. E. Beracochea, C. Weinstein, and D. Evans, 169–182. New York: Springer Pub. Co.

Oyugi, J.O., F.C. Vouriot, J. Alimonti, et al. 2009. A common CD4 gene variant is associated with an increased risk of HIV-1 infection in Kenyan female commercial sex workers. *Journal of Infectious Diseases* 199(9): 1327–1334.

Public Law 101–381. 1990. *Ryan White Comprehensive AIDS Resources Emergency Act of 1990.* Section 2647(a)(1)-(a)(2). http://history.nih.gov/research/downloads/PL101-381.pdf. Accessed 1 June 2015.

United Nations. 2013. *United Nations treaty collection: Chapter IV human rights (8) convention on the elimination of all forms of discrimination against women.* http://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-8&chapter=4&lang=en. Accessed 1 June 2015.

4.14 Case 6: Ethics of Administering Anthrax Vaccine to Children

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4.14.1 Background

Bacillus anthracis is a hardy, spore-forming bacterium that leads to anthrax disease upon infection. The organism has long been considered a likely agent for biological warfare. A weaponized form of the agent would likely result in widespread inhalation anthrax, a severe form of the disease that carries a high (>50 %) case fatality rate. *B. anthracis* spores can last inside the body for weeks before germinating to induce infection and can persist for years in the environment. Anthrax disease is preventable if antibiotics and vaccine are administered prophylactically before someone has symptoms.

The U.S. Centers for Disease Control and Prevention (CDC) and U.S. Department of Homeland Security are concerned about *B. anthracis* as an agent of biological terrorism due to its ease of dispersal, severe health impact, persistence in the environment, and the special public health response it requires (CDC 2013). The U.S. anthrax attacks in 2001 infected 22 people, 5 of whom died, all from inhalation anthrax. The U.S. Department of Health and Human Services prepares for a number of disaster scenarios, one of which is an aerosolized anthrax attack. In this scenario, *B. anthracis* spores are released into the air in a densely populated area, potentially infecting thousands of people.

Children (<18 years) are given special considerations in an anthrax attack scenario, one of which involves receiving the anthrax vaccine, Anthrax Vaccine Adsorbed (AVA). The U.S. Advisory Committee on Immunization Practices recommends giving AVA in conjunction with 60 days of antibiotics for post-exposure prophylaxis of the exposed population against anthrax (Wright et al. 2010). This 60-day antibiotic regimen covers the disease's incubation period and allows for protection before the vaccine takes effect. The vaccine is likely to protect people longer than antibiotics alone and potentially protects against multiple strains of anthrax disease, including bioengineered strains that are resistant to antibiotics (Joellenbeck et al. 2002).

While most of the U.S. population can receive the anthrax vaccine under an Emergency Use Authorization (EUA), children must receive the vaccine under an investigational new drug (IND) protocol as approved by the U.S. Food and Drug Administration. The IND protocol requires informed consent from parents, which is not required under an EUA. The informed consent requirement stems from the lack of safety or efficacy data for AVA in children. Also, due to a requirement under the IND, a subset of the children with IND consent will be asked to enroll in a research IND so that safety and immunogenicity data in children may be obtained during the emergency. The Presidential Commission for the Study of Bioethical Issues debated the study of AVA in children before the event, and has laid out a strict framework for approaching how best to ethically collect these data from a research perspective (Presidential Commission for the Study of Bioethical Issues 2013).

4.14.2 Case Description

A terrorist group has released an anthrax aerosol over a major city in the United States and in a country with a weak public health infrastructure. Of the more than 9 million people in the U.S. metropolitan area at the time, 1.39 million people are exposed, 329,430 of whom are children (Kyriacou et al. 2012). All 1.39 million people exposed will need the vaccine and a 60-day supply of antibiotics to protect them from developing disease. It is unclear what plans have been made to provide prophylaxis to the population living in the other country. In the United States, people thought to be exposed will receive antibiotics and vaccine at points of dispensing (PODs) run by local health departments. The dispensing of antibiotics, which must begin within the first 48 h and finish within 10 days, would require 20 sites providing medicine to 500 people per hour to achieve the goal for the exposed population. Vaccination routinely takes more time and involves additional staff and separate sites to care for the entire population. Additional steps will require more resources and time. Timeliness is essential to ensure those exposed are protected.

In the United States, children needing vaccine come to the vaccination clinic with their parents, slowing the lines to meet the informed consent requirements. Unaccompanied children also show up, slowing the lines to a crawl, as staff attempt to contact parents. The complexity of different vaccine needs for different people, especially those who do not speak English, is overwhelming vaccination staff. To keep lines moving, the staff has created a separate line for families with children, but the slow pace of this line is challenging the clinic's effort to achieve high vaccine coverage rates among children. Tempers flare as families watch adults without children move through the clinic quickly while the family lines grow ever longer. But the parents, who have lots of questions, cannot be rushed to provide their consent. They have been hearing disconcerting media stories highlighting issues related to anthrax vaccine side effects and the lack of testing and safety data. Many parents worry about immunizing their child with an untested vaccine never given to children and posing unknown risks. The vaccination clinic manager, who has had little time to plan, quickly devises the following scenarios to speed decision making:

- Provide parents with the informed consent document and have a public health nurse meet with them to answer questions and discuss concerns about risks and benefits.
- Discuss the informed consent document with a group of families, answering questions and working through concerns about risks and benefits in the larger group, but having a nurse on call to answer confidential questions and speak to families privately.
- Show a large group of families assembled in an auditorium a video produced by the local health department explaining the safety and efficacy profile of the vaccine in adults, and afterward have a nurse discuss with parents the information from the informed consent document and allow parents to ask questions.

4.14.3 Discussion Questions

1. Of the options listed above, which should you choose? Justify your answer in terms of the benefits gained, harms avoided, respect for parental autonomy, privacy and confidentiality, fairness, or other ethical values, such as trust and protecting vulnerable populations.
2. Consider how placing families with children in separate lines affects the distribution of vaccine. Is this the fairest or optimal way to distribute the vaccine? Are there innovative or better options for administering the IND that adhere to FDA rules and achieve maximum vaccination coverage for children? Are these options ethically justifiable?
3. If following the IND protocol for unaccompanied children makes vaccine coverage impossible, what should the vaccine clinic manager and staff do? How would you ethically justify your decision? Would this justification hold if the group in question were all children, not just unaccompanied children?
4. What roles will government trustworthiness and the public's trust in the government play in the vaccination campaign?
5. What ethical concerns are presented by collecting data for research purposes during such an event?
6. The other country under anthrax attack, which is resource poor and lacks public health infrastructure, has received vaccine from the United States, but is under no obligation to follow the mandated U.S. procedures through which antibiotics are administered. To ensure that vulnerable populations are protected against anthrax, what ethical principles, values, and concerns should this country consider? Do these ethical principles, values, and concerns differ from those in the United States? If yes, how? If no, why not?
7. A high percentage of the parents with young children do not speak English. Because the informed consent forms are only in English, translating them will take a lot longer, or an interpreter will need to be available. How would you balance the obligation to protect vulnerable populations with the obligation to maximize coverage?

References

Centers for Disease Control and Prevention (CDC). 2013. *Bioterrorism agents/diseases.* http://www.bt.cdc.gov/agent/agentlist-category.asp. Accessed 3 Jan 2013.

Joellenbeck, L., L.L. Zwanziger, J.S. Durch, and B.L. Strom (eds.). 2002. *The anthrax vaccine: Is it safe? Does it work?* Washington, DC: National Academy Press.

Kyriacou, D.N., D. Dobrez, J.P. Parada, et al. 2012. Cost-effectiveness comparison of response strategies to a large-scale anthrax attack on the Chicago metropolitan area: Impact of timing and surge capacity. *Biosecurity and Bioterrorism* 10(3): 264–279.

Presidential Commission for the Study of Bioethical Issues. 2013. *Safeguarding children: Pediatric medical countermeasure research.* http://bioethics.gov/sites/default/files/PCSBI_Pediatric-MCM_2.pdf. Accessed 2 June 2015.

Wright, J.G., C.P. Quinn, S. Shadomy, and N. Messonnier. 2010. Use of anthrax vaccine in the United States: Recommendations of the Advisory Committee on Immunization Practices (ACIP), 2009. *MMWR Recommendations and Reports* 59(6): 1–30.

4.15 Case 7: Non-adherence to Treatment in Patients with Tuberculosis: A Challenge for Minimalist Ethics

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4.15.1 Background

In Chile, tuberculosis (TB) belongs to the list of "mandatory notification" diseases, a status that allows for the confidential registration and monitoring of cases. Mandatory notification, part of Chile's Communicable Disease Surveillances System, is legally authorized by the 1968 Sanitary Code of the Ministry of Health, specifically the Regulation on Notification of Communicable Diseases (Código Sanitario 1968). By the early 1970s, health authorities created the Program for Control and Eradication of Tuberculosis (PROCET), a model program in its technical conception and application of control measures. The program illustrates how to confront a public health care problem properly through systematically applied, adequate coverage and continuous quality evaluation (PROCET 2005).

Currently, TB prevalence is low in Chile, with the country significantly reducing the disease's mortality and morbidity rates in the closing decades of the twentieth century (Pan American Health Organization 2006). By 2000, this reduction had allowed Chile to cross the eradication threshold (i.e., to reduce the incidence rate below 20 cases per 100,000 people). Over the first decade of this century, however, the pace of reduction in the annual TB incidence rate slowed, decreasing from 7.5 % (1996–2000) to 4.2 % (2000–2005) to just 1.3 % (2005–2010).

This slowing resulted in a 2010 incidence rate of 13.2 cases per 100,000 people—still below the eradication threshold—but falling short of the official target of 10 cases per 100,000 people. To explain the slowing pace, researchers have studied a number of variables, most notably, the role of treatment procedures (Herrero et al. 2011).

To meet the target of 10 TB cases per 100,000 people, PROCET established the following goals: (1) 90 % recovery rate for treated cases, (2) <5 % withdrawals from treatment, and (3) <3 % mortality rate for those undergoing treatment. Achieving these goals requires a stringent treatment regimen that consists of health care workers delivering TB medication on an outpatient basis and directly observing patients while they take their medication. The medications are free for patients within the health care system, including those who have multidrug-resistant TB (MDR-TB).

Analysis of the treatment outcomes for the 2008–2010 cohort of TB patients indicates a recovery rate of 80 %, a withdrawal rate of 7 %, and a mortality rate of 10 % (Ministerio de Salud 2012). Although the latter two numbers are high, analysis reveals that TB treatment continues to be effective, given that the treatment failure percentage, less than 1 %, is quite small. However, the unsatisfactory withdrawal and mortality rates suggest PROCET needs to improve its performance in getting patients to adhere to treatment and in following up more quickly with patients to prevent mortality.

4.15.2 Case Description

Pedro is a 42-year-old divorced father of two. He is a mechanic, but is unemployed and living with his parents.

Diagnosed in 2009 with sputum-smear positive pulmonary TB, Pedro received first-line treatment at an outpatient primary care clinic in Santiago. In October 2009, he moved to the northern part of the country to work as a driver and withdrew from treatment for the first time. While up north, his sputum-smear again tested positive. However, after five attempts in 3 years, Pedro was unable to complete the daily phase of the treatment. As indicated by medical staff, he either refused to attend the local medical center for treatment or rejected the treatment and even verbally attacked staff when they tried to administer medicines.

In January 2012, he returned to Santiago seeking care at the same primary care clinic he had previously visited, continuing to test positive but now presenting respiratory symptoms. A final attempt at treatment, this time with second-line treatment, failed after 2 months due to his irregular attendance at the health care facility and failure to take the medication regularly.

Pedro acknowledged he understood the consequences of his behavior and the possibility of microbial mutations leading to antibiotic resistance, which would change his condition to incurable. Yet, when questioned about the reasons for his behavior, he refused to take responsibility, claiming, among other things, that TB drugs made him feel sick.

In October 2012, he again visited the primary care medical clinic, this time accompanied by his mother and claiming he wanted to "start over." He was feeling ill, having night sweats, losing weight, and had diminished functional capacity that prevented him from working. Because of his previous history, he was now referred to a specialized center, where the physician in charge of the TB program evaluated his case and wrote in his medical records, "The patient does not seem to understand his situation and the risk he is posing to his family…it seems to me that health care personnel are more concerned about patient's disease than the patient himself." The specialist concluded that the chance of the patient completing treatment after six failures was unlikely. The specialist therefore decided not to renew treatment "since this would cause even more microbial resistance. Disciplinary discharge would be more fitting for this patient," the physician added, "especially in view of the great demand for hospital care."

Pedro subsequently revisits the medical center demanding treatment, this time claiming he will not withdraw from therapy because he has joined a church and has had "an awakening of consciousness to the will of God, which is to serve and love your neighbor as yourself, and therefore, not to infect others."

Despite the earlier decision of the physician in charge of the TB program, doctors reevaluate the case and decide that he should receive further TB treatment. Doctors refer him to a social worker for a mental health assessment and the initiation of mental health treatment if needed as a condition of restarting TB treatment.

4.15.3 Discussion Questions

1. Do you agree with the doctors' decision to allow further TB treatment for the patient? Why or why not?
2. Can denial of treatment to a patient with a potentially curable disease be ethically justified, considering that this denial could lead to the patient's death? On what ethical basis should the decision to deny or not deny treatment be made?
3. Given that health resources are limited, what role does the principle of distributive justice play in determining whether patients should be allowed to start treatment after multiple episodes of noncompliance with previous treatment?
4. In view of the risk that the patient could infect his family with TB, should he be denied further treatment or should he be given another chance to complete it? How would you ethically justify your decision?
5. What role should social factors such as educational level, economic status, or family situation play in making such decisions?
6. When a patient could transmit a serious infectious disease, should there be legal enforcement of the requirement to get treated?

References

Código Sanitario. 1968. D.F.L. N° 725/67. *Publicado en el Diario Oficial de 31.01.68.* Gobierno de Chile. Ministerio de Salud. www.bcn.cl/leyes/pdf/actualizado/5595.pdf. Accessed 11 Feb 2014.

Herrero, M., A. Greco, S. Ramos, and S. Arrossi. 2011. From individual risk to social vulnerability: Factors associated with non-compliance with anti-tuberculosis treatment. *Rev Argent Salud Pública* 2(8): 36–42.

Ministerio de Salud. 2012. *Programa Nacional de Control y Eliminación de la Tuberculosis. Informe de Situación 2008 – 2011.* http://web.minsal.cl/sites/default/files/fi les/TB2008-2011.pdf. Accessed 11 Feb 2014.

Pan American Health Organization. 2006. *Tuberculosis: Regional plan for tuberculosis control, 2006–2015.* Washington, DC: PAHO. http://www.stoptb.org/assets/documents/global/plan/tb-reg-plan-2006-15%20AMRO.pdf. Accessed 11 Feb 2014.

Programa Nacional de Control y Erradicación de la Tuberculosis (PROCET). 2005. *Manual de Organización y Normas Técnicas.* Subsecretaría de Salud Pública, Departamento de Prevención y Control de Enfermedades, Ministerio de Salud de Chile. http://web.minsal.cl/portal/url/item/803048171acc60f8e04001011f0148e2.pdf. Accessed 11 Feb 2014.

4.16 Case 8: Mass Evacuation

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4.16.1 Background

Mass evacuation involves moving people (and sometimes their property and animals) to alternative locations to protect them from threats to their health and safety (Kemetzhofer and Weinstein 2012). Threats to public health can be direct or indirect. Direct threats include natural hazards (e.g., hurricanes, floods, earthquakes, wildfires) and human-caused hazards (e.g., release of hazardous materials, nuclear incident, bioterrorist attack). These threats can also negatively affect essential public

services (e.g., water, sewage, electricity) or create conditions for the proliferation of waterborne and vectorborne diseases. Mass evacuation is an important public health response, but it raises practical and moral issues (Settles 2012; Kodama 2015).

The sudden and unpredictable nature of some threats limits opportunities to provide notice for safe, orderly, and rapid evacuation. Such threats often force large numbers of people with different capabilities to travel great distances. Given limited time, resources, and personnel, those requiring assistance in evacuating will need to be categorized according to method of evacuation (e.g., medevac, ambulance, bus) and in what order they should be evacuated.

Although evacuation aims to promote or protect the well-being of the population, its use also raises considerations of fairness. Because evacuation orders may negatively affect vulnerable and marginalized populations disproportionately (Morrow 1999), special attention needs to be paid to these populations (Van Willigen et al. 2002). Public health officials need to consider socioeconomic disparities that can disadvantage community members in ways that impede compliance with evacuation orders. For example, during the 2005 Hurricane Katrina in New Orleans, lack of access to transportation or to financial resources prevented many people from evacuating. To mitigate such disadvantages and deficiencies, evacuation policies and procedures must be established for vulnerable or marginalized populations.

Mass evacuation can be voluntary or mandatory. Most evacuations will be voluntary because most people will comply with the recommendation to evacuate. Nevertheless, implementation seldom occurs without complication, and predicting evacuation behavior of a population is inherently difficult (Baker 1991; Perry and Lindell 1991; Riad et al. 1999; Dash and Gladwin 2007). Evacuations are often ordered by different levels of government and carried out by local responders, requiring a high level of coordination among agencies. Mandatory evacuation adds further complications. Requiring people to leave their homes or work whether or not they consent raises moral questions, such as justifying liberty restrictions.

Whether evacuation is voluntary or mandatory, a small segment of the community will choose not to evacuate, even if they have the ability to do so. In all cases, efforts should be made to educate the public about the personal risks and societal costs of noncompliance with evacuation orders. Those who do not comply with evacuation orders raise the issue of whether they should be forced to evacuate and whether first responders have a moral obligation to go back and rescue them. Enforcement of evacuation orders illustrates how law might be used as a public health tool (e.g., a jurisdiction may criminalize failure to comply with an evacuation order) (Viens et al. 2013).

Attention also has to be paid to the process of returning evacuated populations to their communities. Here, too, both practical and ethical issues arise: the extent to which damaged property and infrastructure should be rebuilt, the level of compensation or restitution that could be paid to evacuees or first responders, and possible sanctions to be levied on nonevacuators later rescued.

4.16.2 Case Description

Your community is a large, metropolitan city under a category 5 hurricane warning. The hurricane, which has been forecasted to make landfall in 48–72 h, threatens massive flooding and property damage. A large number of people widely dispersed in the city will need to be evacuated. They speak many languages, have varying levels of access to transportation, and require various levels of care. Special needs and vulnerable populations (e.g., the disabled, ill and injured, homeless, and the incarcerated) will also need help to evacuate.

As a result of emergency preparedness incident-training simulations, some agencies have developed evacuation plans. These plans are not always easily accessible to all first responders and the lack of coordination between agencies has led to confusion. Responders are unclear about who should be given priority in evacuation assistance, which resources and personnel should be devoted to evacuation efforts, and when to halt evacuation and rescue efforts and shift to recovering bodies. Of particular concern are the number of high-rise commercial buildings and medical facilities in the city. Although these buildings and facilities have individual evacuation plans, most only make evacuation provisions for short-term events, such as power outages or fires. Worse, no central registry or database lists which community members will require help to evacuate.

In less affluent neighborhoods, some residents lack access to a car or sufficient money to transport their family outside the hurricane's path. Some of those unable to evacuate will be able to stay with friends or family. However, evacuees who cannot stay with people they know are quickly overwhelming the capacity of evacuation facilities in nearby towns. Decisions will need to be made about how to coordinate and efficiently use resources and personnel to maximize the number of people protected from the hurricane.

Officials managing the evacuation have realized that mass evacuation raises some logistical and ethical issues shared by public health measures involved in the movement or restriction of people (e.g., quarantine, isolation, social distancing). They have therefore asked you, an experienced public health official, to provide input on which groups of people should be evacuated, how, and in what order of priority. Your special concern in planning and coordinating with other agencies will be the health of the population, mitigating inequalities and the safety of the first responders.

4.16.3 Discussion Questions

1. What are the relevant ethical considerations for deciding who should be evacuated first and whether the evacuation order should be mandatory or voluntary? Of those to be evacuated, who should we evacuate first? How should decisions be made regarding who to evacuate when not all can be evacuated?

2. What role should community engagement play in determining the order of priority of groups to be evacuated?
3. How should authorities deal with those who do not comply with an evacuation order? What are the ethical implications of allowing people not to evacuate? Do authorities have obligations toward people who refuse to evacuate and later need to be rescued? Should people who had the ability to evacuate but failed to do so be blamed or punished in some way when they later need to be rescued?
4. What kind of legal protections are needed to protect people who are made more vulnerable by virtue of having to evacuate? For example, should there be provisions to prevent price gouging on gasoline or to keep extra police officers around to prevent looting?
5. Are those who comply with voluntary evacuation orders owed anything? To what extent must resources be provided for the evacuated population? How much effort should be put into keeping families together? Should compensation be paid when people are asked to evacuate with little time for protecting valuable items that end up getting lost, damaged, or destroyed? How would your answers to these questions change if the evacuation orders were mandatory?
6. In a clinical setting, some patients will be too unstable to be moved or, if movable, will require disproportionate medical care and resources. Would it ever be acceptable to abandon some patients? If so, under what conditions? Would it be morally required that a clinician or first responder stay within the evacuation area with such patients—at greater risk to themselves—to provide constant care until rescue can be provided at a later time?

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References

Baker, E.J. 1991. Hurricane evacuation behavior. *International Journal of Mass Emergencies and Disasters* 9(2): 287–310.

Dash, N., and H. Gladwin. 2007. Evacuation decision making and behavioral responses: Individual and household. *Natural Hazards Review* 8: 69–77.

Kemetzhofer, P., and E.S. Weinstein. 2012. Evacuation. In *Oxford American handbook of disaster medicine*, ed. R.A. Partridge, L. Proano, and D. Marcozzi, 227–237. Oxford: Oxford University Press.

Kodama, S. 2015. Tsunami-tendenko and morality in disasters. *Journal of Medical Ethics* 41: 361–363.

Morrow, B.H. 1999. Identifying and mapping community vulnerability. *Disasters* 23: 1–18.

Perry, R.W., and M.K. Lindell. 1991. The effects of ethnicity on evacuation decision-making. *International Journal of Mass Emergencies and Disasters* 9: 47–68.

Riad, J.K., F.H. Norris, and R.B. Ruback. 1999. Predicting evacuation in two major disasters: Risk perception, social influence, and access to resources. *Journal of Applied Social Psychology* 29(5): 918–934.

Settles, T.L. 2012. Federalism, law and the ethics of disaster evacuations. In *Disasters, hazards and law*, Sociology of crime law and deviance, vol. 17, ed. M. Deflem, 65–81. Bingley: Emerald Group.

Van Willigen, M., B. Edwards, T. Edwards, and S. Hessee. 2002. Riding out the storm: The experiences of the physically disabled during hurricanes Bonnie, Dennis, and Floyd. *Natural Hazards Review* 3: 98–106.

Viens, A.M., J. Coggon, and A. Kessel (eds.). 2013. *Criminal law, philosophy and public health.* Cambridge: Cambridge University Press.