

# *Stigmatization of Not-Knowing as a Public Health Tool*

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**Abstract:** Predictive interventions and practices are becoming a defining feature of medicine. The author points out that according to the inner logic and external supporters (i.e., state, industry, and media) of modern medicine, participating in healthcare increasingly means participating in knowing, sharing, and using of predictive information. At the same time, the author addresses the issue that predictive information may also have problematic side effects like overdiagnosis, health-related anxiety, and worry as well as impacts on personal life plans. The question is raised: Should we resort to stigmatization if doing so would increase participation in predictive interventions, and thereby save healthcare costs and reduce morbidity and premature death? The paper concludes that even if such a strategy cannot be ruled out in some forms and contexts, we ought to be very cautious about the dangers of shame and stigmatization.

**Keywords:** predictive medicine; public health ethics; stigmatization; shame; nudging; predictive information; right not to know; autonomy; human dignity; social justice

## **The Emerging Era of Prediction and its Challenges—Introduction**

Today's medicine bears an increasingly anticipatory face. It is future-oriented, as it more and more focuses on prediction and prevention of possible disease. It opens up new avenues of prevention and therapy but also has the potential to induce new uncertainties and worries. There have been many concerns about an intensified medicalization and pathologization of life through predictive information, with tangible consequences for both individuals and society.

Indeed, paradoxically enough, the objective improvements in medicine and health can be accompanied by a rise in health concerns and complaints.<sup>1</sup> One prominent cause for this is precisely the growing emphasis on prediction. The new "worried well" finds itself in a "semi-pathological pre-illness at-risk state," subjected to constant surveillance.<sup>2</sup> The tendency to perceive and treat risk factors or dispositions as disease or as similar to disease can result in overdiagnosis and overtreatment.<sup>3</sup> Besides that, health-related stress and worry can themselves compromise our physical and mental health.<sup>4</sup>

There are different strategies to cope with biomedical uncertainty; for instance, one may de-dramatize anticipation by fighting statistical and health illiteracy or by reducing so-called affective forecasting biases.<sup>5</sup> Besides well-known psychotherapeutic approaches like cognitive-behavioral therapy, personal and social practices of self-care may also support our immediate trust in our vital body (i.e., yoga, mindfulness). Furthermore, direct political measures can be taken as well; for example, careful regulation of predictive interventions can prevent unwarranted risk awareness and anxiety.

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One may, however, also try to avoid or control the risk system of predictive medicine by referring to the so-called right not to know. Over the last few decades, the right not to know has been recognized both on international and domestic levels, as well as in legal terms.<sup>6</sup> Still, in contrast to the right to know, the theoretical basis of this right has been more contested. In the emerging era of prediction, it is quite possible that the right not to know will increasingly be seen as problematic and outdated, even if it is still recognized and accepted in various regulations.<sup>7</sup>

In light of this horizon, we need to discuss public health tools by which people are encouraged to participate in predictive initiatives and interventions. The scope of such tools can reach from health education and advertisements to nudging and legal restrictions. This paper discusses the ethical acceptability of stigmatization as a public health tool for increasing participation in predictive practices and interventions. Following are three steps in which: (1) the discussions of stigmatizing as a public health tool will be explored, (2) the topic of the right not to know will be discussed, and (3) third, the ethical acceptability of stigmatization of not-knowing as a public health tool will be examined.

### **Stigmatization as a Public Health Tool—Conceptual and Exemplary Discussions**

In his article from 2008, “Stigma and the Ethics of Public Health: Not Can We but Should We,” Ronald Bayer opened a discussion about stigmatization as a tool in public health.<sup>8</sup> Three aspects of these discussions will be explored: (1) the conceptual understanding of stigmatization, (2) the justification and criticism of stigmatization as a public health tool as well as (3) some exemplary fields on which this discussion has been focused (i.e., smoking, nudging, and vaccine refusal).

#### *1) Conceptual Problems*

In his article, Bayer aims to challenge the view that stigmatization is always inimical to public health and contrary to human rights. Particularly against the backdrop of debates about the AIDS epidemic, he shows how the “doctrine of stigma” emerged in public health; that is, how it came to be seen as the “enemy” of public health and as having detrimental effects on both human health and dignity.<sup>9</sup> Bayer’s argumentation was inspired by his study of smoking policy, which he saw as a striking exception to this widely held doctrine. He observes how stigmatization became an efficient, rarely contested, or even welcomed public health tool in tobacco control. “Just as instrumental considerations had informed the opposition to AIDS-related stigma, they now shaped efforts to marginalize and denormalize smoking and smokers.”<sup>10</sup>

Bayer’s most important conceptual distinction is that between a narrow and a broad understanding of stigma. A narrow concept of stigma can be found in such works as Erving Goffman’s classic work *Stigma: Notes on the Management of Spoiled Identity*, which characterizes stigma as profoundly impacting a person’s entire being. In this work, Goffman refers to the “deeply discrediting” effect of stigma and how it reduces someone “from a whole person to one who is tainted or discredited.”<sup>11</sup> Bayer refers, among others, to Gregory M. Herek, for whom stigma involves an “enduring condition” which impacts the “entire identity” of a person, and to Scott Burris, who describes stigma as “a barbarous and unacceptable form of regulation that a humane society must reject.”<sup>12</sup> For these various authors, stigma

perceived in a narrow sense is something dehumanizing, temporally enduring, and which deeply permeates our entire identity.

As an alternative approach, Bayer refers to Bruce Link and Jo Phelan who have argued for a broader, more graduated framing of stigma: "Stigma exists as a matter of degree. The strength of the connection between labels and undesirable attributes can be relatively strong or relatively weak. The degree of separation into groups of 'us' and 'them' can be more or less complete, and finally, the extent of status loss and discrimination can vary. This means that some groups are more stigmatized than others."<sup>13</sup> Bayer explicitly favors this broader and more flexible conceptualization. With regard to a narrow, "dehumanizing" concept he sees no room for ethical justification.<sup>14</sup> Rather, Bayer favors a broad concept which allows for weaker forms and levels of stigmatization; that is, those which are temporary and not enduring, partial and not total and aimed at reintegration as opposed to mere separation, and which, he maintains, can be both instrumentally useful and ethically acceptable.

In addition to this basic conceptual distinction, two other important aspects of stigmatization should be pointed out. First, we have to consider whether stigmatization is related to other-regarding or self-regarding acts. Should the use of stigma (at least in a broad sense) be ethically defensible, it can be important to ask whether the purpose is to prevent other-regarding or self-regarding harms. Second, we have to consider whether or not stigmatization is intentional. Using something as a tool of public health normally means that there is a clear intention to do so. There can be, however, situations in which stigmatization occurs unintentionally (incidentally); that is, as a by-product of another action, without being willed or planned. Such matters also require careful ethical reflection on an important question, which Bayer puts as follows: "...should it be permitted to adopt strategies that will incidentally but *unavoidably* stigmatize behaviors that pose a threat to the public health?"<sup>15</sup>

## 2) *Justification and Criticism*

Bayer notes that even in liberal societies, paternalistic measures are considered a legitimate part of public health, at least to some extent. With respect to other-regarding harms, this is considered quite uncontroversial. However, if we more generally understand paternalism as an integral part of public health, it can also be true with respect to behaviors that are considered as self-harming. To support this point, Bayer refers to examples of persuasive strategies of health education and advertising as well as to more radical measures like behavioral prohibitions and special taxes.<sup>16</sup> Bayer's point is that if we accept paternalism in public health (as, to a certain extent, we generally do), it then becomes not only meaningful but necessary to discuss the use of stigmatization and its effect on social norms and behaviors.

Bayer refers to a number of conditions which should be met to ensure the ethical validity of stigmatization. First, as in human rights-based assessments of rights-limiting measures, the use of stigma should be guided by the principle of proportionality. This means that the severity of the measure should not be disproportionate to the harms that are meant to be prevented. Secondly, several empirical questions have to be considered: "What is the pattern of morbidity and mortality that is the object of concern? Is it the consequence of other-regarding or self-regarding acts? What evidence is there that stigma may affect behaviors and hence reduce disease, suffering, and death? What can be anticipated in terms of the severity, extent, and duration of the suffering that the stigmatized will be compelled to bear?"<sup>17</sup> An

ethical use of stigma would simply not be possible without solid answers to such empirical questions about risks and benefits.

As a last condition of ethical validity, Bayer stresses the need to consider the equity of burdens that are caused by stigma. Bayer recognizes the great significance of the concern that stigmatization (re)produces social inequality and burdens those who are already vulnerable. However, he criticizes the general way that this structural argument has often been raised. For Bayer, to what ends the power of stigma is to be used makes an important moral difference; for example, if it is used to affect social norms to combat sexual violence and homophobia or for other, less defensible ends.<sup>18</sup> He also admits that today, all restrictive and regressive measures in tobacco policy especially burden those at the lower end of society. Still, he maintains that this inequity of burdens may be justified if it helps to reduce the unequal burden of tobacco-related disease. Bayer's point is that even if the use of stigmatization may be burdensome, its drawbacks may still be outweighed by the net benefits, both for vulnerable groups and the entire population (including those who do not start or quit smoking).

What might be some main objections to Bayer's approach? By adapting a broad concept of stigma (concerns of dignity) and discussing paternalism and proportionality (concerns of liberty), empirical validity (concerns of effectiveness), and equity (concerns of social justice), Bayer aims to anticipate potential criticisms of his argument. However, as may be expected, Bayer's defense of stigmatization has been criticized precisely along the lines of these principles of public health. A good example of such criticism can be found in Scott Burris's polemical response, which appeared in the same special issue.<sup>19</sup>

First, Burris rejects Bayer's graduated view of stigma and strongly insists that stigmatization is always "inherently inhumane," that it leads to perfidious forms of self-punishment and should never be used in public health. Second, he questions the effectiveness of stigmatization and sees no solid evidence that stigma might positively contribute to public health. Third, he warns that such public health efforts can be inimical to social justice as they "will add fuel to existing stigmas" of minority groups or classes.<sup>20</sup> Finally, also in regard to liberty, he sees no ethical justification for using stigma. He admits, however, that less restrictive paternalistic measures to signal social disapproval can be useful in public health; for example, negative social marketing and labeling risky behaviors as "undesirable" or "uncool," such as smoking.<sup>21</sup> This latter point, however, indicates that Burris is actually not as far from Bayer as he may at first seem. Rather, the two authors operate with different definitions of stigma and, to some extent, talk past each other.

### *3) Exemplary Discussions*

Bayer's defense of stigmatization as a public health tool was meant to be context-sensitive, and to facilitate careful debate in each and every case as to whether or not it makes for an ethically acceptable strategy. To get a more vivid picture of the arguments used in this debate, it will be helpful to review some exemplary discussions about smoking, nudging, and vaccine refusal. This will be important for later examining the issue of stigmatization of not-knowing predictive information, as it will help to better identify the possible strengths and pitfalls of stigmatization strategy in public health. The first example concerns Bayer's favorite subject: the anti-tobacco policy.

*Anti-Tobacco Policy.* An important critical concern that arises in this context is that of the question of equity and justice in public health. In their commentary on Bayer's article, Kirsten Bell et al. readily admit that different tobacco "denormalization strategies" are increasingly being used by public health actors to represent smoking as an abnormal and unwelcomed activity, and that certain policies—at least implicitly—can endorse a smoking-related stigma.<sup>22</sup> However, they critically question Bayer's optimism, that such strategies can be reconciled with the principle of equity. Bayer agrees that smoking-related stigma can put an additional burden on especially those already marginalized and vulnerable, primarily referring to people in lower income groups. He suggests, however, that such measures can be justified by the long-term benefits that such measures may have on the very same population as they help to reduce disease-related inequity caused by smoking.

Bell et al. see no grounds for such optimism. Their main argument is that, as has been well documented in other areas of addiction, stigmatization will not likely reduce, but rather widen health inequalities as it has negative impacts on access to healthcare. In their view, a growing body of evidence indicates that "denormalization policies" will lead to iatrogenic effects on vulnerable population groups. First, they maintain that such policies are likely to reinforce "a smoking identity," and second, they argue that these policies instigate stigmatizing and discriminatory attitudes among healthcare professionals.<sup>23</sup> For Bell et al., such detrimental effects of tobacco denormalization have not been sufficiently addressed in public health and should deter us from using stigmatization to discourage smoking.

*Nudging.* A second exemplary discussion concerns nudging, shaming, and stigma. In his insightful article "Nudging by Shaming, Shaming by Nudging," Nir Eyal argues that there is an internal and intimate connection between nudging and shaming, "understood broadly to include embarrassment, stigma effects, and any compunction in general."<sup>24</sup> Nudges are supposed to work by softly redesigning choice frameworks or architecture in a beneficial direction, although without making a different choice altogether impossible. As they allow for opting-out, they do not definitively remove certain choices in the way that bans or prohibitions do. In Eyal's view, many nudges work this way because they deploy shame and stigma to affect people's behavior, like zoning laws in tobacco policy, directly observed therapy for tuberculosis or the supersize soda cup ban. Such "slight" and "subtle" shaming usually does not imply "utter humiliation and dehumanization," but can still, nevertheless, effectively influence our choices.<sup>25</sup>

Eyal clearly supports nudging which entails shaming and stigmatization. He points out, however, that their use may be ethically wrong in some contexts as they also can generate pointless and serious shame. He observes that in contrast to nudges, more restrictive measures (mandates, prohibitions) can operate as "good excuses" and do not involve such feelings. Eyal notes that if restrictive measures can have such an advantage over less restrictive ones, the principle of the least restrictive alternative should be critically reexamined.

*Vaccine Refusal.* A final interesting and illuminating example concerns the shaming and stigmatization of vaccine refusal. Recent measles outbreaks across the globe have led public health actors to explore a wide range of strategies to maintain the vaccination rates that are necessary for developing herd immunity. In their article "Shaming Vaccine Refusal" Ross Silverman and Lindsay Wiley critically examine the use of shame and stigma in the context of vaccine refusal.<sup>26</sup> They raise the question as follows: is it justifiable to use shaming (denormalization) to shape social

norms and behavior regarding vaccination, for example via health campaigns that portray vaccine refusal as selfish, irresponsible, and anti-science? In their assessment of that issue, they similarly focus on the four important principles of public health as found in Bayer's article: effectiveness, respect for liberty, respect for dignity, and a fair distribution of burden and benefits (social justice).

Regarding the first matter, Silverman and Wiley find that it is ultimately unclear as to whether shaming and stigmatization are effective and that further research is needed to determine whether denormalization strategies improve vaccine coverage. Considering restrictions on liberty, they identify shame as a choice-guiding disincentive in terms of the Nuffield "intervention ladder"<sup>27</sup> ("guide choice though disincentives"), thereby making it a less restrictive measure than compulsory vaccine laws. With respect to dignity, the key question is that of whether shaming vaccine refusal amounts to a true stigma which is "enduring" and "all-encompassing." For Silverman and Wiley, it does not satisfy these conditions as it is "not so identity spoiling as to be inescapable."<sup>28</sup> Finally, they note that as vaccine refusal is mostly associated with more privileged families, concerns of health justice in this regard are relatively few. Still, they warn that the use of shame can be counterproductive in undermining popular trust in public health efforts and authorities.

### **Predictive Medicine and the Right Not to Know**

Having explored discussions of stigmatization and public health, we now turn our attention to the issue of stigmatization of not-knowing as a tool in public health. It is important to see that such a measure would affect a right that has become well-established in diverse international regulations, even if it has been quite disputed in bioethics, namely, the right not to know.<sup>29</sup> Before focusing on the issue of stigmatization, the moral essence as well as the possible future of this right is considered below.

#### *1) The Right Not to Know and Autonomy*

A key issue in this debate has been a proper understanding of autonomy. As Gert Helgesson shows, the autonomy debate can be conceptualized as a disagreement between two different ideals of autonomy: the control-related autonomy and the decision-related autonomy.<sup>30</sup> His view correlates with a helpful distinction made by Jørgen Husted between a "thin" and a "thick" concept of autonomy.<sup>31</sup>

According to the first ideal, autonomy means to be in control of your decisions. This "being in control" is understood in a specific way: it is especially associated with having information that is relevant to a decision, not just with an absence of external interference. For this view, the right not to know cannot be based on autonomy since autonomy necessarily presupposes having relevant information and understanding. For John Harris and Kirsty Keywood, the use of the right not to know is somewhat similar to selling oneself into slavery. It impacts our self-control in a way which makes it inconsistent with the principle of autonomy. As Rosamond Rhodes puts it: "...when I choose to remain ignorant of relevant information, I am choosing to leave whatever happens to chance. I am following a path without autonomy."<sup>32</sup> From this point of view, the choice of not-knowing can be seen as a choice of slavery—slavery to chance. It can be also seen as a choice of irresponsibility: a choice to decline responsibility for an autonomous, knowledge-based

management of one's health and life.<sup>33</sup> The right not to know may indeed reflect other different interests (privacy and avoiding harm), but it cannot be based on autonomy.

According to the second ideal, autonomy refers to one's own free decisionmaking independent of the controlled interference of others. For this view, the right not to know can very well be based on autonomy provided that it is understood in a sufficiently broad sense.<sup>34</sup> So, Husted distinguishes between a "thin" and a "thick" conception of autonomy. The "thick" or decision-related conception is not concerned with strictly defining the autonomous choice (e.g., as being based on relevant information), but with autonomous life resulting from a "free process of self-creation" and without the controlled interference of others.<sup>35</sup> Thus, autonomy is primarily an achievement of free self-determination or "self-authorship": to live an autonomous life means actively creating "meaning and coherence" and making decisions which express one's very own visions, values, and commitments.<sup>36</sup> The right not to know health information fits well into this concept as it is entirely consistent with the idea that an autonomous person should be able to make decisions for herself.

In view here, the decision-related concept of autonomy seems more plausible. In a peculiar way, the control-related autonomy seems to support a very extensive paternalism as it implies forcing people to know information that they do not want. Even if the idea of "paternalism in the name of autonomy" is not self-defeating per se, as an active policy it would be "oppressively paternalistic."<sup>37</sup> More importantly, the rigorous nexus of autonomy and information characterizing the control-related position seems to be inadequate. Having or acquiring more information does not necessarily mean that we have more control over our lives; on the contrary, our decisions are often based on incomplete information and involve, often favorably, degrees of intransparency. As Peter Wehling puts it in regard to health information: "...a person who feels compelled to acquire ever more knowledge and to continuously make informed choices can swiftly lose control of her life and thus appears to be far less autonomous than another person who follows her own life plans and decides on her own how much and which genetic information she wants to have."<sup>38</sup>

Predictive information has a peculiar ambiguity: it is not always clear if it will really benefit a person. It may have problematic effects like health-related anxiety or severe impacts on personal life plans. This is not to say that health information could not be very relevant to our decisions and autonomy. However, the link between information and autonomy is not as one-dimensional as the control-related concept suggests. As Niklas Juth remarks: "Since it is hard to know whether or not receiving the information in question will actually benefit a certain person, guesses about this should not be the basis of policy or regulation..."<sup>39</sup> This means that concerns about autonomy entangled with concerns about wellbeing convincingly speak in favor of respecting the right not to know as the primary or default policy in healthcare. This can be said both from a consequentialist perspective, according to which rights as "rules of thumb" are seen as serving the purpose of achieving wellbeing, as well as from a deontological perspective of autonomy as a "genuine right."<sup>40</sup>

## 2) *The Shift Toward a Duty to Know*

There are, however, several trends and difficulties that increasingly challenge the right not to know as a primary policy in medicine and public health. We live in

so-called “knowledge-based” societies where knowing is typically considered to be a valuable and responsible attitude. As predictive tests are becoming more and more widely used, it will be hard to work against the stream and be a “savage” in this new era of prediction.<sup>41</sup> The ongoing shift from curative to predictive and preventive medicine makes the practice of not-knowing increasingly difficult to live by. This is a powerful transition that is supported not only by epistemic advances in medicine but also by major players in modern societies (i.e., state, industry, media, and lifestyle trends). According to the inner logic and external supporters of modern medicine, participating in healthcare increasingly means participating in knowing, sharing, and using predictive knowledge.

In modern societies, there has been also an increasing tendency to consider health as the highest good or value in life; that is, health tends to be identified with happiness or the meaning of life. At the same time, health becomes increasingly defined by the anticipatory view of predictive medicine. As Robert Aronowitz puts it: “Reducing risk is no longer a means to health but often its very definition. To comply with screening protocols, have an acceptable number of blood tests or images of scans, and engage in behaviors believed to lower risks, is ...to be healthy.”<sup>42</sup> In light of this, it will be psychologically and socially difficult both to use the right not to know and to uphold it as a primary policy.

Also, rapid advances in predictive medicine are making the question “Who would not want to know lifesaving information?” increasingly suggestive.<sup>43</sup> Benjamin E. Berkman and Sara C. Hull argue that the genomic era has ushered in the time to break from the tradition of the right not to know, as it is simply too much of a reflection of the early stage of genetic testing which primarily focused on a few devastating conditions. Thus, the potentially growing therapeutic value and life-saving potential of testing may overshadow the ambiguities of predictive information, making the choice of not-knowing increasingly difficult.

Finally, we are increasingly being pushed toward a “duty to know” because of the epidemiological transition with a significant increase in costly chronic and lifestyle diseases and of the continuous reforms in post-Fordist healthcare, aiming at cost-containment and quality-improvement through economization and marketization. On the micro-level, economization includes cost-sharing and compliance in prevention and treatment programs, whereas marketization is oriented toward free choice and individual preferences. However, both strategies stress responsibility with respect to prediction and prevention, and the concomitant duties to know and act.<sup>44</sup>

For some observers, these developments bring about a new “somatic ethics” that sees biological embodiment as a site of active choice and responsibility.<sup>45</sup> As Foucault-inspired governmentality studies have shown, such responsibility can be seen as a means of governance, reflecting and reinforcing wider biopolitical rationality. Instead of direct control and coercion, it stimulates self-regulation in an interrelated dynamic of risk, fear, and responsibility.<sup>46</sup> As a consequence, a “biocitizenship society” can be seen as emerging, with corresponding “biovirtues” and responsibilities.<sup>47</sup> As Susan Greenhalgh remarks: “Biocitizenship is so pervasive a feature of our culture and society that it seems that everyone everywhere is lecturing everyone else about being a good biocitizen.”<sup>48</sup> At the same time, “bad biocitizens” who do not live up to health-related expectations can be met with blame and shame. This may happen to not only with apparently healthy people who do not make “right choices,” but also where risks have already occurred.

Biopolitical governance in alliance with market demands can certainly be seen as involved in the development and spread of predictive medicine. However, besides such interests, new predictive interventions also correlate with scientific advances.<sup>49</sup> Likewise, the focus on predictive responsibility can be linked to genuine efforts to help and empower people through early detection, prevention, and treatment. This means that the shift toward a “duty to know” should not be merely associated with the governance and the market but also with epistemic and moral motivations and aims. Altogether, however, they pose a remarkable challenge to the right not to know, both for the individual option and as the default policy in healthcare.

### Stigmatization of Not-Knowing as a Public Health Tool

In light of the foregoing elaborations on Bayer’s thought-provoking article, exemplary discussions of stigmatization (smoking, nudging, and vaccine refusal) as well as on the right not to know, it is now possible to examine the issue of the stigmatization of not-knowing as a tool of public health. In the emerging era of prediction, one’s lack of knowledge about predictive health information can easily be considered as a “biovice” similar to smoking or vaccine refusal, thereby associating it with negative traits like selfishness, irresponsibility, and being anti-science. What are we to say about people who make the explicit, deliberate choice to not know or those who just do not participate (or do not participate enough) in predictive and preventive practices? Would it be acceptable to stigmatize or shame such people if doing so would decrease morbidity and prevents untimely death?

We saw above that in discussions of stigmatization and public health, besides the assumption that the better health of populations is a central (and traditional) ethical goal of public health, mostly four other important principles were considered: dignity, effectiveness, liberty, and social justice. In the following, the focus will be on the same ethical principles. It will also be assumed that in public health ethics, it is necessary to combine and constrain consequentialist objectives related to the well-being of populations with deontological concerns about rights and justice.<sup>50</sup> Ideally, ethical reflection will help public health to “advance traditional public health goals while maximizing individual liberties and furthering social justice.”<sup>51</sup>

#### 1) *Respect for Liberty*

In the context of their discussion about screenings programs, James F. Childress et al. rightly note that “expressing community” (i.e., providing support, encouraging choices, etc.) is often ethically preferable to “imposing community” through coercive policies.<sup>52</sup> Still, in some contexts, the importance of acquiring information has led public health to deploy more restrictive measures. Mandatory screening is rare but has been used, for example, in the context of infectious disease control or the screening of newborns in the United States (e.g., screening of pregnant women for HIV or newborns for PKU and sickle-cell anemia). It has always been very controversial and many have preferred policies like “routine without notification,” “routine with notification,” or in the present day, especially “mandatory offering.”<sup>53</sup> Ruth R. Faden et al. have interpreted such options as being in a (legal) continuum between fully compulsory and fully voluntary regulations.<sup>54</sup> In light of Eyal’s argumentation presented above, this continuum could also be seen as including different “opt-outs” as nudges that, with help of subtle shaming or stigmatization, affect screening-related

behavior and norms.<sup>55</sup> Indeed, these options can be understood as, albeit unintentionally, deploying such hidden dynamics, whereas still being less restrictive than fully compulsory policies.

Newborn screening is somewhat similar to the issue of vaccine refusal since the potential harms involved are clearly other-regarding. Still, what about the stigmatization of not-knowing in contexts of self-regarding behavior? It is not unusual that public health measures aim to protect individuals from themselves, for example, on the grounds of “weak paternalism” (protecting people’s “true interests”) or for utilitarian reasons. Even if they are partly motivated by social concerns about costs, different mandates and prohibitions (e.g., restrictions on certain items) can be seen as helping people to protect their own health.<sup>56</sup>

As discussed above, the individual ambiguity of predictive information regarding its benefits convincingly speaks in favor of the right not to know as being the default policy in healthcare. However, in the emerging era of prediction, it is likely that screening programs with a more clear-cut therapeutic value and benefit will become available if they indeed will.<sup>57</sup> Of course, this must not mean that the right not to know should be abandoned as the default policy. Especially in the context of severe (genetic) conditions in which prediction is uncertain and/or has no therapeutic value, informed consent and nondirectedness of counseling would still be paramount. However, it is to be expected that in some contexts, public health will be inclined to promote the value and need to know predictive information more intensely and paternalistically. In such situations, stigmatization as a choice-guiding disincentive (i.e., nudges, opt-outs, negative social marketing, etc.) would be still less restrictive than selected mandatory “predictive protection helmets.” As Eyal remarks, it “can affect our choices a lot while objectively limiting our freedom of choice only little.”<sup>58</sup> At the same time, such a strategy should be more effective than less restrictive measures and also ethically defensible in other aspects (i.e., importance of condition, availability of treatment and facilities, early recognizability, just allocation, etc.).<sup>59</sup>

## 2) *Respect for Dignity*

A second concern regards the relation between the stigmatization of predictive ignorance and human dignity. It seems clear and uncontroversial that dehumanizing and oppressive stigmatization cannot be ethically defended and clearly seems to be contrary to human dignity. This insight motivated Bayer’s distinction between a narrow and a broad concept of stigma and was also, in fact, the common ground for the heated debate between Bayer and Burris (see above). So, to be defensible at all, stigmatization should be only exercised in very mild or benign forms that would not at all violate human dignity. It should be, for example, temporary and not enduring, partial and not total and aimed at reintegration as opposed to strong separation or “othering”—it should not create “spoiled identities.”

Denying the right not to know by making predictive information generally mandatory would severely violate people’s autonomy and dignity. However, using slight stigma to put mild pressure on people to participate in predictive interventions in certain contexts could be seen as choice-guiding disincentive that is not contrary to human dignity. Silverman and Wiley argue that unlike mental health, addiction, sexual orientation, religion, weight, or skin color, vaccine refusal is eminently mutable, not altogether integral to people’s identity and not socially

visible such that it would amount to a “true” stigma.<sup>60</sup> A similar argument can be made with respect to not-knowing predicative information. Refusing screening is often mutable, not fundamental to one’s identity in many instances and rather limitedly socially visible. A careless denial of the right not to know would undermine it as a genuine right and run contrary to human dignity. The less intrusive measure of enacting a slight stigma could be, however, compatible with dignity.

Of course, one could argue that a stigma which is not detrimental to one’s dignity is not actually serious enough to be called stigma. Burriss along with Silverman and Wiley readily admit that one can find different strategies of denormalization and shaming in public health (e.g., in anti-tobacco policy), which, in their view, do not truly satisfy the conceptual criteria of stigma. Others, like Bayer and Eyal, prefer a significantly broader conceptualization. For Eyal, for instance, nudges can evoke “slight” or “subtle” stigma without normally involving “utter humiliation and dehumanization or a level of shame that threatens personal integrity.”<sup>61</sup> However, regardless of whether we refer to milder forms of social disapproval as stigma, denormalization, or shaming, it is necessary in each and every case to carefully examine the compatibility of these actions with human dignity. There can be smooth transitions in which it could be very problematic and risky to use such strategies.

### 3) Effectiveness

Whether stigmatization can be an effective tool for increasing participation in predictive interventions is unclear, since no specific studies on it seem to have been conducted. Generally, empirical evidence regarding the effectiveness of stigmatization in changing behaviors is quite conflicting. Bayer’s paper was inspired by the use of stigma and denormalization in anti-tobacco policy. Indeed, there are several studies that indicate that stigmatization might be effective in reducing smoking behavior.<sup>62</sup> However, Kirsten Bell et al. argue that denormalization policies will in fact reinforce “a smoking identity.”<sup>63</sup> This claim is supported in recent research by, for example, Marie Helweg-Larsen et al. who performed experiments with the stigma-induced identity threat model and found that stigmatization generated attitudes that dissuaded smokers from, rather than compelled them to, quitting.<sup>64</sup> Nevertheless, their study only focused on heavy smokers and was conducted across a very limited time span. Acknowledging the divergent results of longitudinal studies, they note that further research is needed to determine when and for whom stigmatization is helpful or harmful.

One may conjecture that strong stigma would not only be contrary to dignity but in many situations also ineffective or counterproductive for changing health-related behavior. This idea has invoked “destigmatization” strategies in public health, for example, in the context of HIV prevention. Slight stigma or shame, however, might indeed positively affect and adjust people’s norms and attitudes. This difference would, at least partly, explain why there can be both very pessimistic and very optimistic views regarding the effectiveness of stigmatization.<sup>65</sup> For Eyal, using slight shaming and stigmatization in the context of nudging precisely relies on the assumption that shame is not very restrictive but can, in fact, have a “tremendous impact” on our choices.<sup>66</sup>

However, empirical uncertainty around the effectiveness of stigmatization should make us cautious about whether stigmatization of predictive ignorance could be an effective tool for increasing participation in testing. This uncertainty

complicates both the assessment of alternatives as well as the cost–benefit analysis. Less restrictive tools like health education, enabling choice, gaining trust, and promoting information-positive attitudes should always be the first option. If these tools can be shown to be similar or even more effective than stigmatization and shaming, then the latter would not be justifiable. Solid information about effectiveness is also needed for the cost–benefit analyses. Where the benefits (but also the costs) of stigmatization are of uncertain value, it is very difficult to ensure the proportionality between a measure and its effects.

#### *4) Social Justice*

The shift toward the duty to know described above can be seen, at least partly, to be in tension with ideas of health justice. The focus within “biocitizenship society” on individual responsibility, on individual duties or “biovirtues” to know predictive health information and to act on it can easily overlook the importance of structural, social-ecological interventions. So, for individually oriented stigmatization of predictive ignorance to be defensible (in terms of justice), necessary attention has to be paid to structural efforts to make relevant predictive interventions sufficiently accessible and affordable.<sup>67</sup>

This general justice-related requirement becomes even more pertinent in regard to vulnerable and marginalized groups in society. Stigmatization and shame should not produce social and health inequalities and put an extra burden on those who are already vulnerable. If (even slight) stigmatization and denormalization of predictive ignorance in certain contexts can be expected to have clearly negative impacts on access to healthcare, to alienate people from healthcare providers, to undermine trust in public health and lead to discriminating attitudes among healthcare professionals, such a measure can hardly be justified. All of these concerns need to be adequately addressed in order to ensure that public health policies are in accordance with principles of social justice.

Finally, it has to be considered that stigmatization of not-knowing predictive information may lead people to experience new, disease-related stigmas and to employment and insurance discrimination. The same can also be said, however, about strategies of “expressing community” which “seek to make testing a reasonable, perhaps even moral choice.”<sup>68</sup> Such strategies can also exert soft pressure or even—as an unintended side effect and hidden dynamic—produce slight shame and stigma (cf. Bayer’s rhetorical question about unintended stigma further above). Refusing or failing to be “reasonable” and “moral” can easily be accompanied by feelings of slight shame and embarrassment. This shows that the lines between “normalization” and “denormalization” of health-related behaviors can in fact be quite fuzzy. However, regardless of what strategy is used, it should always be complemented by efforts to destigmatize diseases and to secure people’s privacy and confidentiality.

#### **Conclusion**

A number of conclusions can be drawn from the previous reflections regarding the use of stigma and shame in the context of predictive interventions. First, we are facing the emerging era of prediction, where the right not to know will become increasingly challenged. This paper argued that in this changing situation, the right

not to know should be upheld as the default policy in healthcare. Furthermore, it seems clear that the use of strong, dehumanizing, and degrading stigma is very difficult to justify, both in the context of predictive interventions and in public health in general. However, the use of slight stigma and shame (in nudging, opt-outs, and negative social marketing) cannot be ruled out in some contexts of predictive care; they can be unintentionally involved even in positive strategies for promoting information-positive attitudes. A slight stigmatization of predictive ignorance would not necessarily be contrary to human dignity or liberty. Still, the use of such a strategy should, in each and every case, be scrupulously examined in relation to liberty, dignity, effectiveness, and social justice. Open and critical questions should not be taken lightheartedly and there are good reasons to be very cautious about the dangers of shame and stigma. The (often hidden) workings and triggers of stigma should be more carefully studied, as should the context of predictive interventions and trends.

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