

## 3

## Transparency Trade-offs: Priority Setting, Scarcity, and Health Fairness

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### I INTRODUCTION

Legal and ethical arguments for transparency, including transparency in health care and policy, frequently frame transparency as a civil right of broad value to all. According to this view, transparency may conflict with other values such as privacy, but there are no interpersonal trade-offs: offering transparency to some individuals does not preclude or conflict with offering it to others.

In contrast, this chapter argues that we should understand transparency in a different way. Rather than viewing transparency as a right, we should regard it as a finite resource whose allocation involves trade-offs. It then argues that those trade-offs should be resolved by using a multiprinciple approach to distributive justice that incorporates values of welfare, autonomy, and priority to the least advantaged. Even those who are not persuaded by the second thesis may find the first thesis and the frameworks for evaluating those trade-offs valuable.

The chapter proceeds as follows: Part II provides a definition of transparency. It also distinguishes several categories of transparency – benefit/burden transparency, procedural transparency, and personal transparency – and clarifies that the chapter’s focus will be on benefit/burden transparency. Part III defends the claim that efforts to achieve benefit/burden transparency inevitably involve trade-offs, because interests in receiving information vary across time and context within the same individual, and also vary between individuals. Part IV discusses several different approaches to resolving these trade-offs, drawing on existing work on distributive justice. These approaches include maximizing welfare, maximizing autonomy, and giving priority to the worst off. It argues that benefit/burden transparency should be apportioned using a multiprinciple approach that incorporates several distributive

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values. Part V examines some of the implications for law of recognizing the trade-offs presented by transparency proposals.

## II DEFINING AND CATEGORIZING TRANSPARENCY

Before making the case that pursuing transparency involves trade-offs, it is crucial to define transparency, yet much work on the topic curiously bypasses this first step. Transparency is a difficult term to define, and has typically not been defined clearly. Angus Dawson complains that

despite its ubiquity in contemporary bioethics, I'm not sure what the term transparency means. After all, transparency is just a metaphor suggesting that we make things visible. It is not, in itself, either a moral principle or a key part of any substantive moral theory; so it is hardly a surprise that the invocation of transparency offers us only modest help in moral disputes.<sup>1</sup>

What do we want from a definition of transparency? For transparency to merit its status as a topic of interest for bioethics and law, it must be defined in a way that captures some aspect of what we care about. However, Dawson is right that transparency is unlikely to be a value of fundamental importance. Even if we are pluralists about what is valuable, rather than transparency being an object of value in itself, transparency is more likely to serve as a means to achieving valuable ends, such as better health or improved patient autonomy.

One reason to define transparency is that a good definition can ensure that transparency is distinct from other frequently discussed values. This resembles the value of avoiding redundancy when interpreting legal language. If a proposed definition rendered transparency identical to some other already-discussed value, that would be a point against it.

What the metaphor inherent in the concept of transparency suggests is clarity: transparency involves simple access rather than concealment or obscurity. Accordingly, I will define transparency as *easy access to relevant information*. This definition resembles the definitions offered by several scholars. Vaccaro and Madsen, in a business ethics context, define transparency as “the degree of completeness of information . . . provided by each company to the market concerning its business activities”<sup>2</sup>; Vishwanath and Kaufmann define transparency as the “increased flow of timely and reliable economic, social and political information”<sup>3</sup>; and Fred Schauer defines transparency as information, processes,

<sup>1</sup> Angus Dawson, *Transparency, Accountability, and Vaccination Policy*, 35 *J. Med. Ethics* 274, 274 (2009).

<sup>2</sup> Antonino Vaccaro & Peter Madsen, *Corporate Dynamic Transparency: The New ICT-Driven Ethics?* 11 *Ethics & Info. Tech.* 113, 117 (2009).

<sup>3</sup> Tara Vishwanath & Daniel Kaufmann, *Toward Transparency: New Approaches and Their Application to Financial Markets*, 16 *World Bank Res. Observer* 41, 42 (2001).

or facts being “open and available for examination and scrutiny.”<sup>4</sup> A recent article focusing on health care claims that transparency involves “making available to the public, in a reliable and understandable manner, information on the health care system’s quality, efficiency and consumer experience with care.”<sup>5</sup>

The provision of health care and the promotion and protection of health involve numerous types of information. As a shorthand, I will call the dimension of transparency on which I focus *benefit/burden* transparency, since it involves access to information about the health benefits and burdens of various interventions. Examples of these interventions are products and services that promote or threaten health. The clearest category of products that promote health are pharmaceuticals and medical devices. Many foods, beverages, and consumer goods also serve to promote health. Meanwhile, food and drink, as well as consumer goods and household and industrial chemicals, can also jeopardize health. The most important services that promote health are those of physicians, nurses, and other health care providers.

Efforts to promote benefit/burden transparency include calls for improved product labeling, and other information provision, on foods, beverages, pharmaceuticals, and medical devices.<sup>6</sup> Transparency principles have been proposed for health services as well as health-related products – for instance, some have suggested “report cards” for hospitals or health care providers that describe patient outcomes in absolute and/or comparative terms.<sup>7</sup>

Many other aspects of health provision, health care, and public health also raise issues of transparency. One frequently discussed issue is *procedural* transparency – that is, transparency regarding how private and public governance decisions are made. (There can even be “transparency transparency” – that is, procedural transparency about decisions regarding benefit/burden transparency.) Some have argued that procedural transparency requires that the bases for decision making, including evidence employed by decision makers, be made clear and open to all.<sup>8</sup>

Information about individuals’ health status also presents important questions, which frequently contrast transparency with personal privacy or concealment. Discussions around data sharing and stored samples in biomedical research, as well as familiar public health debates around contact tracing, involve questions of what I will call *personal* transparency.

<sup>4</sup> Frederick Schauer, *Transparency in Three Dimensions*, 2011 U. Ill. L. Rev. 1339, 1343 (2011).

<sup>5</sup> Zahava R.S. Rosenberg-Yunger & Ahmed M Bayoumi, *Transparency in Canadian Public Drug Advisory Committees*, 118 *Health Pol’y* 255, 255 (2014).

<sup>6</sup> E.g., Andrea Freeman, *Transparency for Food Consumers: Nutrition Labeling and Food Oppression*, 41 *Am. J. L. & Med.* 315, 317–21 (2015).

<sup>7</sup> See Steven D. Findlay, *Consumers’ Interest in Provider Ratings Grows, and Improved Report Cards and Other Steps Could Accelerate Their Use*, 35 *Health Aff.* 688, 693–95 (2016).

<sup>8</sup> E.g., Ross E.G. Upshur, *Principles for the Justification of Public Health Intervention*, 93 *Can. J. Pub. Health* 101, 102 (2002).

While procedural and personal transparency are important for health, my focus in what follows will be on benefit/burden transparency.

### III TRANSPARENCY AS A FINITE RESOURCE

My first core claim is that efforts to promote benefit/burden transparency inevitably involve trade-offs, both between the informational interests of the same individuals in different contexts and between the interests of different individuals. This is because benefit/burden transparency typically involves choosing to highlight specific information about a given intervention, and a given piece of information is more helpful for some individuals and in some contexts than it is for other individuals and in other contexts.

Potential trade-offs between transparency and other values are widely recognized. Some, for instance, worry that transparency threatens privacy and trust.<sup>9</sup> My focus, in contrast, will be on the existence of trade-offs *internal* to transparency.

One way of understanding the existence of trade-offs within transparency is to consider the contrast between rights and goods. In a famous essay, Jurgen Habermas explores the distinction between these two concepts: goods promote interests or values and can be distributed among individuals, whereas rights are constraints on the distribution of goods – as Habermas puts it, rights “cannot be assimilated to distributive goods without forfeiting their deontological meaning.”<sup>10</sup> The existence of trade-offs within transparency suggests that transparency should not be understood as a deontological right, but instead as a good or interest. A recent scholarly article argues that understanding transparency as an interest helps in adjudicating trade-offs:

Among the reasons to prefer an instrumentalist position on transparency rights is that it allows the interests protected by transparency rights to be weighed against losses created by these protections in a familiar consequentialist fashion. By conceiving of transparency rights instrumentally, we can also distinguish in principle between relevant and irrelevant disclosures of information in a fashion that rights to know founded in the intrinsic value of knowledge or autonomy cannot easily accommodate.<sup>11</sup>

An instrumental understanding of transparency not only helps in distinguishing relevant from irrelevant information, but also in weighing the benefits of a given transparency policy for some against the benefits of a different policy for others.

<sup>9</sup> See, e.g., Sandrine Baume & Yannis Papadopoulos, *Transparency: From Bentham’s Inventory of Virtuous Effects to Contemporary Evidence-based Skepticism*, *Critical Rev. Int’l Soc. & Pol. Phil.* 1, 11–14 (2015).

<sup>10</sup> Jurgen Habermas, *Reconciliation Through the Public Use of Reason: Remarks on John Rawls’s Political Liberalism*, 92 *J. Phil.* 109, 114 (1995).

<sup>11</sup> John Elia, *Transparency Rights, Technology, and Trust*, 11 *Ethics & Info. Tech.* 145, 146 (2009).

Some transparency trade-offs will be interpersonal: a choice that improves transparency for some people could reduce transparency for others. Consider an analogy, likely familiar to many: in choosing the strength of a prescription for eyeglasses, providers cycle through numerous lenses, asking which provides the best view. The lens that provides the clearest view to me will rarely be the type that provides the clearest view for you. Transparency also presents trade-offs that are intrapersonal rather than interpersonal, because ways of presenting information that are transparent in some contexts may not be equally so in others. Again, consider eyeglasses. In some contexts, individuals want to see close-up detail; in others, they want to see far away. Similarly, in some contexts, individuals want to be shaded from the sun, and in others they want every last glimpse of light.

One might object that the analogy with eyeglasses indicates the *absence* of a trade-off. Typically, eyeglasses can be personalized to suit each person's needs and preferences: you will rarely need to look through my glasses. However, transparency in health care typically cannot be personalized in this way. Foods, drugs, and pharmaceuticals do not display personalized labels to different consumers, but instead have a single label. Even if different patients can ask their doctors different questions, the framing and presentation of an initial interaction cannot typically be individualized. Transparency typically involves presenting a set of information to all comers, even if different individuals may focus on different parts of that information, rather than presenting different initial information to different individuals.

That transparency cannot be perfectly suited at once to all individuals' interests presents an inevitable trade-off. We have limited space and time to present information, and must choose which information to make prominent and accessible. Some people may be very interested in the financial costs of using a service or product. Others may be more interested in the medical risks and benefits; among this group, different individuals will be interested in different medical risks and benefits. Yet all these individuals will be purchasing the same product or using the same service, which means that the product's labeling (for example) typically will be the same, even though different consumers have different informational needs.<sup>12</sup> Furthermore, fulfilling some individuals' interests in knowing about health care products and services will frequently compete with fulfilling other individuals' interests.

Many of the questions raised by informational and transparency policies resemble those raised in debates over "nudges." Like nudges, transparency efforts do not straightforwardly subsidize or proscribe certain choices. However, informational transparency efforts – like nudges – will tend to systematically favor certain options and individuals over others. Accordingly, they will pose some of the same questions

<sup>12</sup> Michelle Meyer discusses the problems that heterogeneous interests pose for safety, rather than transparency, regulations in her *Regulating the Production of Knowledge: Research Risk-benefit Analysis and the Heterogeneity Problem*, 65 *Admin. L. Rev.* 237 (2013).

of distributive justice that nudges inevitably do.<sup>13</sup> Transparency does not simply serve as an overlay that preserves existing patterns of distribution, but shifts those patterns in specific directions. Unless transparency is explicitly designed to preserve the distributive status quo, it will change that status quo in a variety of ways.

One source of trade-offs is the scarce space available for presenting information. Labels on medicines, or on foods and drinks, are scarce real estate that can only present a limited amount of text.<sup>14</sup> Furthermore, even within this scarce real estate, certain positions are more valuable than others: people are more likely to attend to items at the top or middle of a label than items at the bottom, and more likely to pay attention to information or warnings that are larger or placed on the front of a product than on the back.<sup>15</sup> Similarly, informed consent processes typically only present a limited range of the imaginable costs and benefits of an intervention – in order to avoid the problem of a consent form that is interminably long, certain risks and benefits must be foregrounded.

Moving from space to content, it is challenging to make the presentation of information neutral between different individuals' interests. Merely presenting information creates inferences that the information in question is relevant or important – otherwise, why would it be presented? The relative prominence of different types of information may affect judgments about the importance of that information. Achieving expert agreement about what information is correct and important can also be challenging. These challenges are exacerbated by the fact that information provision typically involves questions of values as well as questions of purely technical fact.

Another trade-off reflects the fact that some individuals have a preference not to know about some features of products.<sup>16</sup> For instance, calorie labeling can change the enjoyment of a meal or even encourage some individuals with eating disorders to make unwise choices, even as it provides valuable information to others.<sup>17</sup> Forced disclosure of information to decision makers who have already made their minds up – as occurs in some reproductive choice contexts – can also be contrary to some

<sup>13</sup> See Matthew A. Smith & Michael S. McPherson, Nudging for Equality: Values in Libertarian Paternalism, 61 *Admin. L. Rev.* 323, 328 (2009).

<sup>14</sup> See *Robinson v. McNeil Consumer Healthcare*, 615 F.3d 861, 869 (7th Cir. 2010); *Finn v. G.D. Searle & Co.*, 677 P.2d 1147, 1153 (Cal. 1984).

<sup>15</sup> See, e.g., John Grishin et al., Improving Food Labels for Health and Safety: Effects of Ingredients List Placement on Search Times, 60 *Proc. of the Hum. Factors and Ergonomics Soc'y Ann. Meeting* 1637, 1641 (2016); Gyorgy Scrinis & Christine Parker, Front-of-Pack Food Labeling and the Politics of Nutritional Nudges, 38 *L. & Pol'y* 234, 237–38 (2016).

<sup>16</sup> Cf. Suzanne M. Miller, Monitoring and Blunting: Validation of a Questionnaire to Assess Styles of Information Seeking Under Threat, 52 *J. Personality & Soc. Psychol.* 345, 351 (1987).

<sup>17</sup> On threats to enjoyment, see, e.g., Nicolas Cornell, The Aesthetic Toll of Nudging, 14 *Geo. J.L. & Pub. Pol'y.* 841, 852–54 (2015); on eating disorders, see, e.g., Ann F. Haynos & Christina A. Roberto, The Effects of Restaurant Menu Calorie Labeling on Hypothetical Meal Choices of Females with Disordered Eating, 50 *Int'l J. Eating Disorders* 275, 278–80 (2017).

individuals' informational interests.<sup>18</sup> Similarly, a medical report card or information about side effects might provide valuable facts to some patients but lead others to become fearful and avoid treatments that would be substantively beneficial.<sup>19</sup> The Food and Drug Administration has, in amicus briefs and its own guidance documents, taken the position that excessive warnings could discourage the use of a drug by patients who are likely to benefit.<sup>20</sup>

Questions about transparency and information presentation arise not only for regulatory authorities, but also for manufacturers, retailers, and health care providers. Particularly under a regime where regulatory intervention is weak – as in the United States – manufacturers, retailers, and providers face ethical decisions about what sort of transparency to provide about product ingredients and likely effects.

I will use food labeling as an example of the numerous trade-offs involved in transparency. A simple can of food includes a variety of health-relevant labels.<sup>21</sup> On the front of the can, the label provides a name for the food, the name of the food's manufacturer or brand, and likely a picture as well. It also describes the quantity of food in the can, and may feature other information such as whether the food is organic or kosher and whether it contains transgenic ingredients. On the back, the label includes information about the caloric content of the food, some of the nutritional content, and the ingredients in the food. In some cases, the label will be printed in only one language; in other cases, it will be printed in multiple languages.

All these labeling decisions involve trade-offs and priority-setting decisions. For instance, the choice to include information about whether a product is organic or contains transgenic ingredients both implies the importance of this information and occupies space and attention that could have been devoted to other information. Listing the quantity of sodium on the main part of the label, while listing vitamins and other minerals elsewhere, takes the position that knowledge about sodium content is more valuable. Leaving some information, such as food miles traveled or micronutrient content, entirely off food labels means that individuals who especially value that information will have to try harder to obtain the information they are seeking.

These issues that crop up in food labeling also apply to other forms of information disclosure for health care and health promotion, such as health care provider report cards, designs for medical bills and pharmaceutical price statements, and public health disclosures such as warnings about infectious disease threats or toxic chemicals. All of these disclosures are offered in a single form to the public at large.

<sup>18</sup> Govind Persad, *Libertarian Patriarchalism: Nudges, Procedural Roadblocks, and Reproductive Choice*, 35 *Women's Rts. L. Rep.* 273, 277–84, 292–93 (2013).

<sup>19</sup> Ronald M. Epstein et al., *Withholding Information from Patients – When Less Is More*, 362 *New Eng. J. Med.* 380, 380–81 (2010).

<sup>20</sup> See *Tucker v. SmithKline Beecham Corp.*, 596 F. Supp. 2d 1225, 1230, 1230 n.5 (S.D. Ind. 2008).

<sup>21</sup> Carrie Griffin Basas, "V" is for Vegetarian: FDA-Mandated Vegetarian Food Labeling, 4 *Utah L. Rev.* 1275, 1285–86 (2011).



## IV DISTRIBUTING TRANSPARENCY FAIRLY

If transparency decisions involved no trade-offs among the interests of different individuals, they would involve no issue of distributive justice. The proper framework to think about transparency would instead be (solely) a framework of civil rights and freedoms, where – at most – the interest of sellers in not being regulated, or in speaking freely, would be compared to the interest of the public in obtaining information. Transparency itself would not be the distribution of a good among individuals, but rather the fulfillment of consumers' rights.

However, the fact that transparency decisions inevitably involve setting priorities makes them a proper subject for analysis through a lens of distributive fairness. Problems of distributive fairness in health are familiar in other contexts, such as priority setting for global health funding or determining who should receive specific scarce resources such as organs or vaccines in a pandemic. In these contexts, some have suggested that these priorities be set using a single principle for distribution, such as the principle of maximizing population health or the principle of treating people identically.<sup>22</sup> The former principle has been operationalized in approaches that aim to maximize the quality-adjusted life-years (QALYs) achieved by providing a given intervention, while the latter has been operationalized in approaches that use random selection to choose between individuals. In other work, I have argued for using a multiprinciple approach that combines several different principles of distributive justice to decide what to do. Still others, most prominently Norman Daniels, have eschewed principles altogether in favor of relying on whatever judgments are produced by bodies deliberating under certain procedural rules.<sup>23</sup>

This subpart pursues the positive aim of developing and applying a multiprinciple distributive framework to the problem of fairly distributing the benefits of transparency. In doing so, it first examines how several different distributive frameworks for health – including welfare maximization, autonomy maximization, and priority to the least advantaged – might be applied to the case of transparency. It then argues for a multiprinciple approach that combines these values.

## WELFARE MAXIMIZATION

One approach to setting priorities for transparency is simply to choose the transparency regime that maximizes overall welfare, broadly considered. However, even this

<sup>22</sup> For a review of these proposals, see Govind Persad et al., Principles for Allocation of Scarce Medical Interventions, 373 *Lancet* 423 (2009). A population-health-maximizing approach to allocation is defended in Peter Singer et al., Double Jeopardy and the Use of QALYs in Health Care Allocation, 21 *J. Med. Ethics* 144 (1995); An identical-treatment approach is defended in James F. Childress, Who Shall Live when Not All Can Live? 53 *Soundings* 339 (1970).

<sup>23</sup> See generally Norman Daniels & James Sabin, Setting Limits Fairly: Can We Learn to Share Medical Resources? (2002). But see Annette Rid, Justice and Procedure: How Does "Accountability for Reasonableness" Result in Fair Limit-Setting Decisions? 35 *J. Med. Ethics* 12 (2009) (critiquing this approach).



approach involves a variety of choices. The primary choice involves deciding how to define welfare. Some law and economics scholars have suggested understanding welfare as a matter of wealth maximization.<sup>24</sup> However, this is implausible because individuals value goods other than wealth – for instance, individuals typically are willing to trade some wealth for health improvements or for a more fulfilling career. More common definitions of welfare focus on the improvement of human capabilities, on individuals' subjective experiences, on the satisfaction of preferences, or on individuals obtaining some set of objective goods.<sup>25</sup> Which definition is selected will in turn affect which approach to transparency is chosen.

Many legal frameworks for evaluating regulatory transparency use – or claim to use – a welfare-maximization approach, namely, cost–benefit analysis.<sup>26</sup> Health care frameworks that use cost-effectiveness analysis also regard welfare maximization as their ultimate goal. Welfare maximization has the appeal – at least superficially – of being neutral. It also represents a principled and easily operationalizable alternative to ad hoc decisions about labeling. However, it also faces well-known problems.<sup>27</sup> We typically care about more than welfare maximization – in particular, we often care about the well-being of specific individuals or of the least advantaged. We also care about other values, such as autonomy.

Some might respond that the right way to incorporate other values, such as the well-being of the least advantaged or autonomy, is to regard the transparency process simply as a vehicle for welfare maximization, and then to use some other mechanism – such as taxation – to promote values other than welfare maximization, such as the well-being of the least advantaged.<sup>28</sup> This approach is frequently favored by economists. But it faces several problems. First, transparency regulations might empirically prove to be a more effective way of promoting nonwelfare values than a later redistributive process would be.<sup>29</sup> Second, some of the nonwelfare values at issue – such as autonomy – have a closer conceptual connection to transparency, such that a welfare-maximizing approach to transparency might not be able to later redistribute in order to promote autonomy.<sup>30</sup>

<sup>24</sup> E.g., Richard A. Posner, *Wealth Maximization Revisited*, 2 *Notre Dame J.L. Ethics & Pub. Pol'y* 85 (1985).

<sup>25</sup> See, e.g., Simon Keller, *Welfarism*, 4 *Phil. Compass* 82 (2009).

<sup>26</sup> Matthew D. Adler, *QALYs and Policy Evaluation: A New Perspective*, 6 *Yale J. Health Pol'y, L., & Ethics* 1, 58–61 (2006) (discussing FDA's use of cost–benefit analysis to analyze a disclosure rule).

<sup>27</sup> Alexander Volokh, *Rationality or Rationalism? The Positive and Normative Flaws of Cost–Benefit Analysis*, 48 *Hous. L. Rev.* 79, 82 (2011); Douglas A. Kysar, *Politics by Other Meanings: A Comment on "Retaking Rationality Two Years Later,"* 48 *Hous. L. Rev.* 43, 76–77 (2011).

<sup>28</sup> See generally Louis Kaplow & Steven Shavell, *Fairness versus Welfare* (2002).

<sup>29</sup> Zachary Liscow, *Note, Reducing Inequality on the Cheap: When Legal Rule Design Should Incorporate Equity as Well as Efficiency*, 123 *Yale L.J.* 2478, 2482–85 (2014) (arguing that equity-informed legal rules are better equipped than taxes for reducing income inequality).

<sup>30</sup> Cf. S. Andrew Schroeder, *Consequentializing and Its Consequences*, 174 *Phil. Stud.* 1475, 1483–84 (2017).

Accordingly, I conclude that while considering the welfare implications of transparency is important, fairly distributing benefit/burden transparency requires doing more than maximizing welfare.

#### AUTONOMY MAXIMIZATION

Transparency is often regarded as a way of promoting individual autonomy, rather than individual well-being. Accordingly, another way of approaching the problem of priority setting would be to focus on transparency's informational role and instead aim to maximize the extent to which the choices in question are autonomous. This requires providing some definition of autonomy; possibilities include the extent to which the decision reflects the considered judgments of the decision maker, or the extent to which the decision reflects the decision maker's true or deep values.<sup>31</sup>

As with welfare maximization, autonomy maximization faces the problem that we care about more than autonomy. One might reply that even if we care about other values, the point of transparency is to promote autonomy. But this is incorrect. Many defenses of transparency identify values other than autonomy – such as population welfare or improvement of individual health and capability – as part of the case for promoting transparency.

#### PRIORITY TO THE LEAST ADVANTAGED

Another way of approaching the problem of how to set priorities for transparency is to design transparency in such a way that it protects and assists the least advantaged. While the value of assisting the least advantaged is widely identified as important, the question of who counts as the least advantaged is contested – for instance, should transparency focus on the interests of those who are least advantaged overall, or least advantaged with respect to health alone?<sup>32</sup> Even with respect to health, there are complicated issues in determining who is worst off with respect to health. Some see being worst off as being sickest right now, while others see it as having the worst health over one's lifetime.

There are also questions about whether to focus on the immediate effects of transparency (whether transparency promotes access to some form of health care and reduces unintended harm) or, also, to consider the more remote effects of informational transparency. For instance, transparency requirements could raise the price of certain health care interventions, making it more difficult to access

<sup>31</sup> Sarah Buss, *Personal Autonomy*, *The Stanford Encyclopedia of Philosophy* (2013), <https://plato.stanford.edu/archives/win2016/entries/personal-autonomy/>, archived at <https://perma.cc/RM7Q-V5JC>.

<sup>32</sup> Daniel Sharp & Joseph Millum, *Prioritarianism for Global Health Investments: Identifying the Worst Off*, 34 *J. Applied Phil.* (2015), doi: 10.1111/japp.12142, sections 6 and 7.

them even while making the interventions themselves more valuable to their recipients.<sup>33</sup>

#### MULTIPRINCIPLE APPROACHES

In work on the allocation of scarce, lifesaving medical resources, I have defended a multiprinciple approach that considers four principles of distributive justice – treating people equally, maximizing utility, assisting the worst off, and promoting and rewarding usefulness.<sup>34</sup> Allocating time and space for benefit/burden transparency efforts – most of which involve medical interventions that are not immediately lifesaving – is a different problem with less immediate stakes, and calls for different principles. What is appropriate where scarce, lifesaving resources are concerned may not be appropriate elsewhere. People who receive less useful information are in a quite different position from people who lose out in priority setting for scarce organs or vaccines. This difference makes the principle of treating people equally (through first-come, first-served or lottery procedures) less important, because the downside of losing out and the upside of gaining an intervention are both much smaller, and there is no obvious way to use queuing or lotteries to design labeling.<sup>35</sup> Principles of promoting and rewarding usefulness are similarly less important. In contrast, principles of maximizing utility and priority to the least advantaged remain important. Additionally, the close relationship of information to autonomy makes autonomy an especially important consideration in the labeling context.

Accordingly, I defend a multiprinciple strategy that combines principles of welfare promotion; respect for and promotion of autonomy; and protection and assistance to the worst off. Even though none of these principles are sufficient on their own to settle questions of how transparency should be provided, none of them are flawed principles that undermine the merit of a multiprinciple approach that includes them.<sup>36</sup>

Consider the application of this multiprinciple approach to the case of food labeling. In deciding which pieces of information should receive priority, we should consider the overall benefits to the population as a whole, but should also look at

<sup>33</sup> On higher prices as an effect of food labeling, see Elise Golan et al., *Economics of Food Labeling*, 24 *J. Consumer Pol'y* 117 (2001); on price transparency, see Margaret K. Kyle & David B. Ridley, *Would Greater Transparency and Uniformity of Health Care Prices Benefit Poor Patients?*, 26 *Health Aff.* 1384 (2007).

<sup>34</sup> Persad et al., *supra* note 22, at 423–26; Govind Persad et al., *Standing by Our Principles: Meaningful Guidance, Moral Foundations, and Multi-Principle Methodology in Medical Scarcity*, 10 *Am. J. Bioethics* 46, 47 (2010); Govind Persad, *Public Preferences About Fairness and the Allocation of Scarce Medical Interventions*, in *Interdisciplinary Perspectives on Fairness, Equity, and Justice* 53–56 (Meng Li & David Tracer eds., 2017).

<sup>35</sup> That is, the “fair chances/best outcomes” problem identified by Norman Daniels is less urgent where transparency is concerned. See Norman Daniels, *Rationing Fairly: Programmatic Considerations*, 7 *Bioethics* 224 (1993).

<sup>36</sup> On this distinction, see Persad et al., *supra* note 22, at 423.

whether the information is important to making an autonomous decision about the product in question and to maintaining one's autonomy in the future. We should also consider how the information bears on the welfare and autonomy of those who are most disadvantaged with respect to either welfare or autonomy. As an example of how this would work, we might consider whether information about a given nutrient is especially valuable to people in general or to the least advantaged; whether this information is important to making an autonomous decision in light of what we know about people's values; and how ways of presenting this information would bear on autonomy.

This section concludes with a brief comment on the alternative strategy of eschewing principles altogether in favor of procedural rules. The same concerns about using this approach to allocate scarce medical resources apply in the transparency context as well. Even after procedural rules are optimized, those engaged in a fair decision-making process must still have some recourse to substantive principles in order to reach decisions within that process.<sup>37</sup> Fair procedures, while important, are not an alternative to substantive principles – rather, fair procedural rules should be coupled with some principles of distributive justice. The principles suggested here are offered as potential guides on which decision makers may rely.

## V LEGAL IMPLICATIONS

What are the legal implications of recognizing trade-offs within transparency, and designing those trade-offs in light of a multiprinciple approach to distributive justice?

Matthew Adler has recently discussed the use of cost–benefit information in creating labeling requirements.<sup>38</sup> Once we recognize the importance of multiple principles, this might motivate moving away from a simple cost–benefit or cost-effectiveness analysis toward some type of analysis that incorporates a greater plurality of values. Some of these approaches include extended cost-effectiveness analysis (ECEA) and social-welfare function approaches that include values other than welfare.<sup>39</sup>

Another implication of using a multiprinciple system of transparency is that information presentation might properly vary not just by the type of good at issue, but by the likely consumers of the good and by the interests that the good promotes or threatens. Right now, caviar and chicken nuggets are labeled in the same way.

<sup>37</sup> Dan Brock, *Ethical Issues in the Use of Cost Effectiveness Analysis for the Prioritization of Health Care Resources*, in *WHO Guide to Cost-Effectiveness Analysis* 289, 291 (T. Tan-Torres Edejer et al. eds., 2003) (“[M]uch important work remains to be done on the substantive issues of equity in health care, and that work should inform the deliberations of those taking part in . . . fair procedures.”).

<sup>38</sup> See Adler, *supra* note 26.

<sup>39</sup> Matthew Adler, *Social Welfare Functions*, in *Global Health Priority-Setting: Beyond Cost-Effectiveness* (Ole Norheim et al. eds., forthcoming 2018); Stephane Verguet et al., *Extended Cost-Effectiveness Analysis*, in the same volume.

But – if we are concerned with autonomy promotion and with the interests of the least advantaged – it might well make sense to allow greater variation in caviar labeling, given that caviar consumption is less closely tied to autonomy or to the interests of the least advantaged. The same might be true for transparency regarding different types of medical services – a physician report card for an emergency room physician or rural family medicine provider might contain different information from that of an ophthalmologist or orthodontist. In contrast, the labeling of goods frequently purchased by the least advantaged or by individuals who experience challenges in autonomous decision making might need to be tailored to protect these individuals, just as consent processes sometimes need to vary when specific vulnerable populations are being enrolled in medical research.<sup>40</sup> This would support an approach to benefit/burden transparency that focuses on the individuals and interests affected by transparency, rather than on specific physical categories of goods and services such as foods or medicines.

Another implication of conceiving of benefit/burden transparency as a good is the strengthened case for judicial caution. For issues that are purely matters of individual civil rights and liberties, courts are frequently well placed to make decisions. In contrast, there is good reason for courts to be much more cautious when intervening in systems of health care priority setting that involve inevitable trade-offs.<sup>41</sup> Concerns about the judicialization of health care provision have been raised in countries that recognize an individual, justiciable right to health.<sup>42</sup> In the United States, similar worries have been raised about lawsuits that challenge allocation procedures for scarce medical resources such as organs and vaccines, and more generally about individually justiciable legal claims that bypass an allocation system.<sup>43</sup>

As such, courts should be more willing to intervene in issues of procedural and personal transparency than in disputes regarding benefit/burden transparency. Benefit/burden transparency, which involves the distribution of a scarce resource – informational space – is a topic better considered by agencies and legislatures. However, the importance of affording some sort of appeals process for questions of distributive justice means that judicial systems will likely need to maintain some involvement in evaluating benefit/burden transparency proposals.

<sup>40</sup> Rebecca L. Sudore et al., *Use of a Modified Informed Consent Process Among Vulnerable Patients: A Descriptive Study*, 21 *J. Gen. Internal Med.* 867, 871 (2006); see also Suzanne V. Arnold et al., *Converting the Informed Consent from a Perfunctory Process to an Evidence-Based Foundation for Patient Decision Making*, 1 *Circulation* 21, 27 (2008).

<sup>41</sup> Alex Voorhoeve et al., *Three Case Studies in Making Fair Choices on the Path to Universal Health Coverage*, 18 *Health and Hum. Rts.* 11, 18–20 (2016). But see Keith Syrett, *Courts, Expertise and Resource Allocation: Is there a Judicial 'Legitimacy Problem'?*, 7 *Pub. Health Ethics* 112, 120 (2014).

<sup>42</sup> See generally Alicia Ely Yamin & Siri Gloppen, *Litigating Health Rights: Can Courts Bring More Justice to Health?* (2011).

<sup>43</sup> See, e.g., Scott D. Halpern, *Turning Wrong into Right: The 2013 Lung Allocation Controversy*, 159 *Annals Internal Med.* 358, 358 (2013).

A final aspect of conceiving of benefit/burden transparency as a distributive justice issue is that distributive justice frequently involves inquiries that are highly empirical and quantitative. Comparatively few empirical inquiries are required when granting or protecting a civil right, because the interest at stake is an individual one. Granting a civil right immediately confers on an individual the legal ability to perform a given action without sanctions or penalties. In contrast, improving benefit/burden transparency is more akin to setting tax or allocation policy, where selecting the best tax or resource allocation regime involves empirical examination of the effects of different policies. Even though benefit/burden transparency implicates autonomy in addition to well-being, assessing the effect of certain interventions on individual autonomy should also be possible.

## VI CONCLUSION

This chapter has argued that transparency should be approached as a problem of distributive justice. The challenge of trade-offs in transparency reflects the fact that transparency involves offering a one-size-fits-all regime to people whose interests differ over time, and across different people who may have different interests. It is therefore interesting to consider whether advances in personalized medicine will reduce the trade-offs involved in transparency.<sup>44</sup> If each intervention could be targeted to a specific person, labeling and information as well as physiological efficacy could be tailored to person and context. These individualized interventions would present fewer interpersonal trade-offs.<sup>45</sup>

However, many types of goods, such as staple foods and public health interventions that affect populations rather than discrete individuals, are unlikely to become personalized. Accordingly, we will face the challenge of balancing the desire to personalize and individualize interventions with the fact that trade-offs will sometimes be inescapable. Just as this is a challenge in setting guidelines for other population-affecting rules such as formularies, drug pricing, and practice guidelines, it will also be an ongoing challenge in designing transparency.

<sup>44</sup> Cf. Jeffrey J. Goldberger & Alfred E. Buxton, *Personalized Medicine vs Guideline-Based Medicine*, 309 *JAMA* 2559 (2013).

<sup>45</sup> See a similar suggestion of replacing IRBs with individual risk-benefit evaluation in Meyer, *supra* note 12, at 299.