

University of Tartu  
Institute of Philosophy and Semiotics

**Valuing Health: Against the Ethical View**  
**Master's Thesis in Philosophy**

Jay Zameska

Supervisor: Kadri Simm

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## Forward: situating this thesis

My thesis can be considered a part of bioethics broadly construed. Bioethics is a large field, focusing on ethical issues that arise from medicine and the biological sciences. It overlaps with (or encompasses, depending on your perspective) the fields of medical ethics, public health ethics, healthcare ethics, etc. We could roughly say that whereas medical ethics is usually focused on clinical medicine, healthcare ethics is concerned with the healthcare system more generally. My thesis is primarily related to the intersection of bioethics (or if you prefer, healthcare ethics) and health economics. Health economics focuses on the functioning of healthcare systems, as well as on health-related behaviors (consumption of alcohol, for example). Health economics is a major part of most contemporary health systems, which typically strive for efficiency in use of resources and rely on health economics to develop and

apply notions of efficiency in healthcare. There is a great deal of overlap between health economics and healthcare ethics, especially relating to questions of justice and distribution in healthcare.

My thesis deals with one narrow range where health economics and healthcare ethics overlap. It focuses on how one of the fundamental values in health economics is established: the value of health. Health – what it is, and how to value it – is itself a major area of both philosophy and health economics. My focus is not on the conceptual-philosophical aspects (What is health? What is the value of health?), but instead on the proposed ethical justification of a particularly prominent set of approaches to valuing health, often grouped under the title “preference-based measures.” These measures establish the value of health states through aggregated public preferences. My question is not “What is the value of health?” but “Is this way of valuing health ethically sound?”

I aim to investigate one of the key ethical assumptions in preference-based methods of valuing health – that valuing health shows respect for persons, a key notion of healthcare ethics – and challenge this assumption. I argue that showing respect for persons through respecting their preferences requires respecting their autonomous preferences, and only their autonomous preferences. I then argue that we should doubt whether the preferences used in preference-based measures of valuing health really are autonomous. This matters for conversations in both health economics and healthcare ethics. It may give us a reason to prefer different methods of valuing health, and it gives us a reason to reconsider how we traditionally think about autonomous decision making in healthcare contexts. To put it simply, my thesis exists at the blurry edges of healthcare ethics and health economics.

## Introduction

Health is often valued by its contribution to well-being. The most common way to establish values for health states is through eliciting a sample population’s preferences among states. The *evidential view* supports using preferences based on the idea that these preferences provide reliable indicators of well-being. The *ethical view* takes eliciting preferences to show proper respect for persons. There have been many severe criticisms of the evidential view, but as of yet, little to no discussion of the ethical view supporting preference-based methods for valuing health. In this thesis, I explain the process of valuing health states (Section 1), and

describe the evidential and ethical views (Section 2-2.2). I explain how preference-based measures are supposed to show respect for persons (Section 2.2), and that respect for persons is shown by respecting autonomous preferences, and *only* autonomous preferences (3.1). I argue that health state preferences are not autonomous preferences (3.2-3.6), and as a result, preference-based measures do not show respect for persons, and so they are not actually supported by the ethical view. I explain the consequences of this argument for preference-based measures of health valuation (Section 4), suggesting that this gives us a reason to prefer methods that value health on other bases, such as through opportunity or capability. I also suggest that this has consequences for how we should think about the notion of autonomous choice in healthcare contexts, and propose that bioethics needs sustained philosophical investigation into the actual processes of patient decision-making.

### 1.) Background: why health measurement matters

Many of the most pressing issues encountered in public healthcare policy require measuring and comparing health outcomes. Questions like “Should we adopt policy A or B?” or “How should we set healthcare priorities?” are questions that fundamentally rely on adequate measures of health. This is not just a technical or economic exercise: the ethics of healthcare also require measurement. Classic ethical principles – for example, priority to the worst-off – also require measurement. Without adequate measures of health, there is no way to know who is the worst-off, much less who in a given population benefits (and by how much) from the various policies under consideration. The centrality of health measurements is reflected in the kinds of difficult questions that frequently arise in healthcare ethics:

- Who should receive priority in treatment?
- What kinds of treatments should a given health system support?
- What populations are ‘the worst off’ in terms of health?
- How well is the health service functioning? (and for who?)
- Who should receive limited resources under scarcity?
- Etc.

What all of these questions share is their dependence on measurement. None of them can be adequately answered (nor their answers implemented) without suitable systems of measurement. And what we seek to measure is health (or rather, the value of health). But

when thinking about these kinds of questions, it is not specific health measures like cardiac function or joint mobility that are relevant. Instead, its *generic health measurement* (GHM) that matters – in other words, how healthy someone (or a population) is *as a whole* or *all things considered*.

Generic health measures have many uses, ranging from population research to clinical medicine. Typically, different uses require different measurement approaches. In this thesis, I'm primarily interested in what are called "*summary measures of population health*" (SMPH). SMPH are a kind of generic health measure used to represent and compare the health of populations. These kinds of measures often play a role in the process of deciding the distribution of health resources. I'll focus on one particular kind of summary measure of population health, called "Quality Adjusted Life Year" or "QALY." Despite many criticisms of QALYs, as well as some inherent limitations of the approach, QALYs continue to be a popular and prominent method of measuring health. For example, UK's National Institute for Health and Care Excellence (NICE) uses QALYs to perform cost-utility analysis. The UK's National Health Service relies on the resulting "£ per QALY" to evaluate the efficiency of their health service (Culyer, 2012, p. 276). Although QALYs are particularly prominent in health economics and public health administration, they also feature in many philosophical arguments, especially those focused on distributive justice in health care.<sup>1</sup>

The primary difference between population research health measures and allocational health measures is the level of precision required. Allocation of health resources requires us to have more precision or to make finer distinctions in health states, in order to discriminate among alternative policies (Hausman, 2015, p. 5). Further, allocation in public healthcare systems often requires support from a local political consensus – in other words, measures of health for allocational purpose need to conform to local values, at least to some extent (Hausman, 2015, p. 5). This notion of conformity to local values will be relevant later, when I discuss the "Ethical view" that underwrites preference-based measures like QALY.

The key fact about generic health measures is that they need to capture the aspects of health that matter to our goals or purposes – in this case, policy evaluations. As a result, a generic health measure should be (1) scalar, (2) cardinal, and (3) interpersonally comparable

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<sup>1</sup> See, for example, the work of John Harris, Alan Williams, Peter Singer, Norman Daniels, etc.

(Hausman, 2015, p. 5). Further, it should measure what matters to people about health, and be precise enough to be useful in allocation decisions. I'll return to the question of reflecting what matters to people about health later (Section 2.4).

So far, I've explained a bit about *why* we want to measure health, and I've given some criteria a health measurement should meet. But so far, I haven't actually addressed our ability to measure it.

### 1.1) Approaches to valuing health

Generally speaking, there is broad agreement that what summary measures of population health aim to measure is the value of health, rather than health itself (Hausman, 2012; Hausman, 2015; Bognar, 2008). Regardless of the philosophical definition of health selected, there is no way to compare whether someone with a broken wrist or broken ankle is "healthier" without some reference to the value of unbroken wrists and ankles. It is precisely these kinds of questions that we need to answer in population health: e.g. should we prefer to treat hearing issues or vision issues in a particular population? Deciding whether or poor eyesight or poor hearing is "healthier" or "less healthy" depends on an appeal to their value. However, this brings out another question, the question that is central to my thesis: how should we establish the value of a particular health state? This section surveys various approaches to valuing health states.

So far, I've explained that what we really care about in health is its value (sometimes also called "health impact"). This value is usually in terms of the consequences that health states have on things that people care about. So, health economists and epidemiologists really aren't focusing on measuring the *amount* of health, but the value of health. When it comes to valuing health states, there are a number of different approaches. Some seek to measure health's value by its impact on opportunities (Daniels, 1985; Hausman, 2015). Others have focused on capabilities (Sen, 1993; Venkatapuram, 2011; Prah Ruger, 2010). Still others take a more directly economic "human-capital" approach (Brock, 1993, p. 122). However, the most popular and prominent approaches have focused on measuring the effects of a health state on individuals' well-being (Broome 2002, Brock 2002, Bognar 2008, Hausman 2015).

The way that the impact on well-being of a particular health state is usually determined is through eliciting individual preferences among health states, and then aggregating them into

a general value for each health state. One of the most common and well-known of these well-being based approaches is the “QALY” or “Quality Adjusted Life Year.” In the next section, I explain the basics of the QALY approach as an example of how preference-based measures are constructed. I then explain the evidential and ethical justifications for preference elicitation.

## 1.2) QALY: a preference-based measure of health value

How should we decide what priority to assign to various competing healthcare interventions? Given the limited nature of health care resources, we need to know both about the interventions’ effects on health outcomes and their costs. The trouble is, different kinds of interventions yield different outcomes, and so it can be hard to compare them. An intervention designed to prolong life or increase survival rates of a disease might be able to be measured by examining the resulting change in mortality rates. But not only does this ignore all of the other life factors that we want to know about the outcome – often grouped under the title ‘Health-Related Quality of Life’ (HRQoL) – it also makes it incomparable with programs designed to provide pain relief, or improve mobility. The ‘natural units’ of these interventions (years of life saved, pain reduced, etc.) are not directly comparable. Instead, we need some way to compare them – we need a common unit of health that captures both length of life and HRQoL impacts. However, as explained in the previous section, we don’t seek out to measure health directly. Instead, we seek to measure the *value* of health. This is where Quality-Adjusted Life Years (QALYs) and other preference-based measures enter the picture.

QALYs are a component of “Cost-Utilities Analyses” (CUAs) that seek to compare treatments and interventions by their impacts on well-being (Oliver, 2003, p.8). The utilities in QALYs are a kind of preference weighting – the background assumption is that the stronger someone prefers a particular health outcome, the more value it has (Weinstein et al., 2009, p. S5). This means that the ‘value’ of health states in QALYs are based on people’s preferences for different health states, and the more valuable (i.e. more preferred) states will receive a greater ‘weight’ in analyses (Weinstein et al., 2009, S5). This kind of approach is explicitly (preference) utilitarian in its structure and theoretical background, but it can be accommodated by non-utilitarian frameworks. Certain assumptions that are typically associated with QALYs (for example, that the goal of health care allocation is to maximize health outcomes, or that the

system should be blind to distributional concerns) are not necessarily part of the QALY methodology (Williams, 1996, p. 1803).

The preference-based utilities used in QALYs are measured on a cardinal scale from 0-1, with “0” representing death, and 1 representing full health. Although the 0 and 1 are arbitrary (though natural) choices, this is an interval scale, so the intervals are meaningful: a change from .1 -> .2 is equivalent to .7 -> .8. Generally, states worse than death are acceptable, with those states being ranked as a negative value (Weinstein et al., 2009, S5). The point of assigning values together on an interval scale is to allow for a ‘common currency’ to enable comparison among different kinds of interventions.

All of the above is important, but it is not the focus of my concerns here. I’m most interested in the way the values of health states (also called ‘quality weights,’ ‘health utilities’ or ‘HRQoL weights’) are established. Fundamentally, what this valuing means is that individuals assess different health states and place a value on each of them. These individual values are then aggregated, and a quality weight for a health state is established. So how do we find out how individuals’ value different health states? This is where Time-trade offs (TTO) and Standard Gambles (SG) enter the picture.

### 1.3) Gambles, trade-offs, and other ways to value health states

The basic way to establish health state values, as explained above, is by eliciting individuals’ preferences among various health states.<sup>2</sup> Standard QALYs typically rely on *ex ante* respondent groups – that is, they rely on members of the public who have not experienced the health states in question (Nord et al., 2009, S14).<sup>3</sup> However, simply asking individuals if they prefer one health state to another does not provide much information (it may provide an ordinal ranking, but not a cardinal ranking). As a result, a variety of methods are used to develop cardinal preference rankings. Here I’ll focus on the two primary methods: Time trade-

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<sup>2</sup> A note on terminology: members of the public who are asked to establish values for health states are often called “informants” or “respondents.”

<sup>3</sup> Although it is standard to rely on *ex ante* groups (and that is my focus here) there are possible alternatives, such as relying on *ex post* groups, healthcare professionals, current patients, etc. (Nord et al. 2009; Dolan 1999). There is ongoing debate about who should be asked. See for example, Dolan 1999 for an overview the problem.

offs and standard gambles.<sup>4</sup> In what follows I'll briefly explain the function of TTO and SG valuation exercises, before turning towards the conceptual and ethical motivations behind this family of preference-based approaches.

*Time trade-offs* (TTOs) present individuals with a choice between two alternative scenarios. The choice is between living the rest of their life (usually a given period of 10 years) in an impaired health state (e.g. type 2 diabetes) or living in full health for a shorter period of time. This shorter period of time in full health is adjusted until the individual is indifferent between their options. What this tells us is how much time an individual would be willing to sacrifice to avoid a particular health state. To use the example above (10 years of type 2 diabetes vs. X years of full health) the indifference point is 8 years – that is, this individual (or aggregate of individuals) sees 8 years of full health as equivalent in value to 10 years with diabetes (Whitehead & Ali, 2010, pp. 8-9; Oliver, 2003, p. 9). The result ( $8_{\text{healthy}} \text{ years} / 10_{\text{diabetic years}}$ ) is a HRQoL weight of 0.8. See figure 1 below for an illustration of TTO.

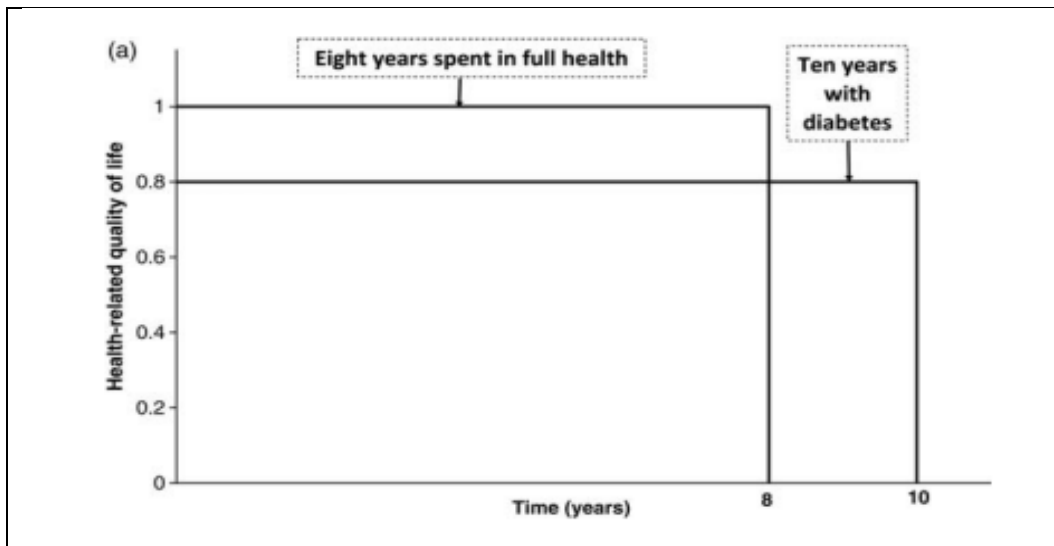


Fig. 1: TTO Scale from Whitehead & Ali, 2010, p. 10

<sup>4</sup> Readers may notice that I have left out Visual analog scales (VAS), which are almost always discussed in the literature on QALY methodology. Although always discussed, VAS are generally not as often used, except as a 'warm-up' for other methods, because they are susceptible to severe scaling biases (end-of-scale biases, and equal-spacing bias) (Cf. Whitehead & Ali 2010, Weinstein et al. 2009).

The *Standard Gamble* approach is similar to TTO, but involves an element of risk, hence the ‘gamble.’ The gamble is a choice between remaining in a particular health state or taking a gamble: either you’ll return to full health or you’ll die, with the probability of death varied until the individual is neutral between the certainty of staying in the health state and the risks of the gamble. The fundamental idea behind the standard gamble is that the worse a health state is, the higher the risk of death an individual would accept to be cured (Whitehead & Ali, 2010, pp. 9-10; Oliver, 2003, pp. 10-11). See figure 2 below for a standard SG decision tree.

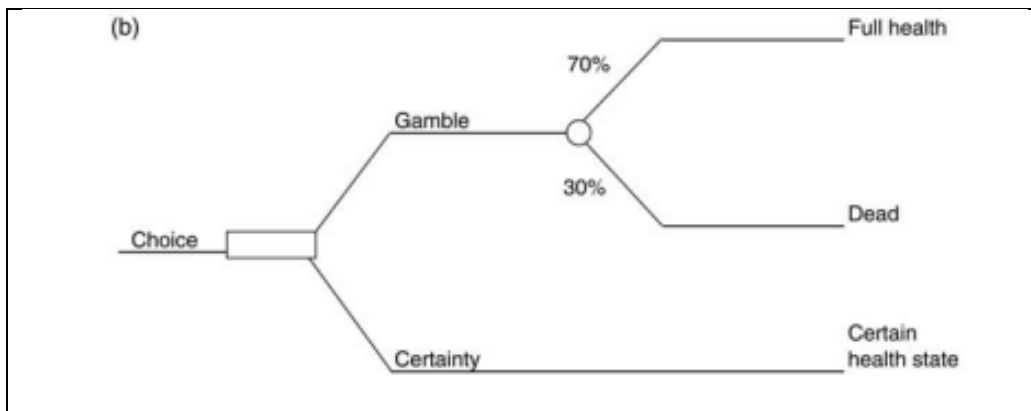


Fig. 2: SG tree from Whitehead & Ali, 2010, p.10

Regardless of which approach is adopted, they all have the same fundamental basis: the value of individual health states is determined by (aggregated) individual preferences between health states. Although I’ve given a brief overview of how these kinds of valuations are constructed and conducted, I have not yet addressed *why* preferences are taken as the appropriate basis for health state valuations. There are a few different answers; one is a purely historical and not so enlightening answer: health economics largely grew out of welfare economics, which has a strongly utilitarian basis. As a result, health economics adopted the same kind of fundamental assumptions as welfare economics, such as ‘preference = utility.’ However, there are at least two other strong reasons why preferences continue to be taken as the appropriate basis for valuing health states. First, preferences might be thought to be a good indicator of individual well-being, even if preference-satisfaction does not necessarily constitute well-being. Call this the *evidential view*. Second, respecting individual preferences in this area might be thought to show a proper respect for persons – a longstanding focus of

healthcare ethics. Call this the *ethical view*. First, I'll address the standard evidential view. Then I'll address the ethical view: the role that respect for persons has in motivating preference-based approaches to valuing health states.

## 2.) Why preferences?

In this chapter I explain the methods and motivations of preference elicitation to determine the value of health states. I explain that there are two (usually complimentary) views supporting preference-based approaches. First, the *evidential view* sees individual's preferences as a good indicator of well-being. Second, the *ethical view* sees relying on public preferences as a way to show respect for persons. My focus is on the ethical view.

### 2.1) The evidential view: preferences as a guide to well-being

In the previous section, I explained how summary measures of population health (SMPH) are typically calculated by relying on public preferences to reveal the relationship between health and well-being. In this section, I briefly explore one justification for the use of preferences: the so-called *evidential view* (Hausman & Mcpherson 2009, p. 16; Hausman, 2015, p. 77). This view argues that while preference satisfaction may not directly constitute well-being, preferences may still be good evidence or guides for well-being. In this section, I briefly explain the evidential view and its criticisms, before turning my attention to the much less explored second supporting view – the ethical view.

The evidential view is, roughly, that in favorable circumstances, preferences can be a good (though fallible) guide to well-being (Hausman & Mcpherson, 2009, p. 16; Hausman, 2015, pp. 76-79). This is based on the *assumption of evaluative competence*. This assumption claims that in favorable circumstances (understood as when individuals have access to all the relevant information, and are free of flaws or limitations in rationality) there is good reason to defer to individual judgment about what is good for them (Hausman, 2015, p. 77). This can be stated strongly (that in the right circumstances individuals are good judges of their best interests), or more weakly (that there is no reason to think third parties are in a better position to know what is in a particular individual's best interests). This assumption is rather

demanding – it requires complete information, deliberative rationality (understood as complete and transitive preferences, uninfluenced by reasoning flaws or biases), and that the agent’s preferences are appropriately self-interested (Hausman, 2015, pp. 76-77).

It is these exacting standards and informants’ failures to meet them that have led many to criticize the assumption of evaluative competence. These criticisms range from highlighting the flawed nature of informants’ reasoning, to arguing that informants lack any meaningful way to obtain full information, as well as demonstrating the lack of complete and transitive preferences. Further, they often emphasize the fact that people’s health evaluations are rarely directly and solely self-interested (cf. Hausman, 2015, Chapter 8, for an overview of all of these problems). All of the above violates the requirements of the assumption of evaluative competence, and so provides good reason to reconsider how much support the evidential view actually offers for preference-based methods of health valuation. In short, the evidential view has come under severe criticism recently, and this criticism gives us good reason to doubt the project of establishing health values by relying on informants’ stated preferences (Hausman, 2015, p. 103).

However, despite these evidential shortcomings, we may still decide there are good reasons to rely on individual preferences. We might think that there are ethical reasons to prefer a valuation system that relies on public preferences to settle these difficult questions about value. In the next section, I examine the notion that these kinds of preference-based methods are supported by another view: *the ethical view*. This is the notion that eliciting public preferences among health states shows the proper respect for persons that liberal democratic societies’ healthcare systems require.

## 2.2) The ethical view: preferences as respect for persons

As discussed above, respecting preferences is often thought to be a way to promote well-being. But it is also sometimes justified on the grounds of *respect for autonomy* or *respect for persons*. Although these two aspects of preference satisfaction are not always clearly distinguished, they are separable. For example, despite the evidential problems with preference-based methods, we might be inclined to rely on them for ethical reasons. There is already plenty of evidence and argumentation that respecting preferences need not lead to higher well-being; often it leads to the opposite. But far less attention has been paid to the

distinctly ethical aspect: that respecting preferences shows respect for autonomy. My aim is to criticize this second view: respecting preferences doesn't necessarily respect autonomy. I have focused on one particular area that depends heavily on preferences: health state valuations. But some of this argument may be generalizable to other contexts as well. In this section, I explain respect for persons and the role it plays in supporting preference-based measures of valuing health.

The ethical view is not so widely discussed at present. The most direct formulation of it can be found in Alan Williams' defense of the QALY measure, which he largely pioneered and popularized (MacKillop and Sheard, 2018, p. 23). It may be because the use of this measure is now so well-accepted that debates about it tend not to focus on the explicit ethical justification in favor of preference-based methods as such, but instead tend to focus on other ethical issues with the use of QALY – such as the way it discounts the value of the disabled, or the way in which it may discriminate against the elderly (Cf. Brock, 2004, for an overview of these issues). However, the fact that the ethical motivation for relying on preferences is not widely discussed does not mean that it does not exist – it clearly does, but has unfortunately been neglected. Here, I explore this ethical view. I highlight how Williams grounds the use of (public) preferences in the notion of respect for persons or respect for autonomy, and discuss the brief historical development of the concept in bioethics. I start by briefly tracing the development of the concept of respect for persons, before turning to Williams' claims about how this notion applies to QALY.

Respect, in our everyday language, is a rich and complex term. It is perhaps unsurprising that the term “respect for persons” contains a similarly rich and complex set of meanings. This is especially so in healthcare ethics, where respect may be urged for everything from autonomy, to cultural differences, to patient privacy, and on to many others. I will not attempt to trace all possible uses of the term “respect for persons” and its associated terms and concepts, nor will I aim to give an extensive history of the term(s). Instead, in this section I give a brief history of the notion of respect for persons in bioethics, tracing its origins from Kant and Mill to its contemporary understanding in bioethics. My aim is to clarify how the substantive notion of respect for persons took on its particular understanding in contemporary bioethics as respect for persons *qua* autonomous agents.

The origin of respect for persons in bioethics traces back to Kant, whose influential account of respect for persons laid the groundwork for all later approaches to respect for persons. In Kant's view, all persons are owed a certain kind of respect simply by the fact that they are persons. For Kant, respecting persons means respecting persons as ends in themselves. This notion is fundamental to Kant's moral philosophy, as it underwrites his categorical imperative: "Act in such a way that you use humanity, as much in your own person as in the person of any other, always at the same time as an end and never merely as means" (Kant 1785/2002 p. 4:429). Kant established this notion of respect for persons as a fundamental moral duty. Later developments of Kant's account came to focus more explicitly on the notion of autonomy (understood as personal autonomy, distinct from Kantian moral autonomy) as the primary expression of respect for persons. In so far as we respect people for being the kind of rational beings who can direct their own lives, we need to respect their capacities for autonomy – that is, we need to refrain from undermining their ability to make autonomous choices, and we need to respect their autonomous choices once they are made.

John Stuart Mill developed a similar vein of thought about respect for persons. Mill's understanding of respect for persons as respect for personal autonomy established much of the basis of contemporary bioethics. Mill never explicitly used the term "respect for persons," but the development of his anti-paternalistic liberalism strongly influenced later understandings of what it means to "respect persons." Mill famously contends that individuals must be free to exercise their own "perception, judgment, discriminative feeling, mental activity, and even moral preference" (Mill 2003/1859 p. 123). Mill considers these faculties "the distinctive endowment of a human being" and recognizes that they are primarily expressed through individuals' choices (Mill 2003/1859 p. 123). As such, Mill proposes, we need to respect individuals (self-regarding) choices.

The notion that respect for persons is expressed through respecting persons' choices sets the stage for the development of contemporary accounts of respect for persons in bioethics and its related fields. The emphasis on choice that Mill develops begins the shift from respect for persons as respect for persons *tout court* to respect for personal autonomy, where autonomy is focused on the notion of choice. Respect for persons shifts from being respect for persons (*qua* human beings) to respect for persons (*qua* autonomous agents) (Lysaught, 2004, pp. 675-676). Much of the famous early work in Bioethics reflects this almost immediately.

Paul Ramsey's *The Patient as Person* (1970) places the notion directly in the title, while *The Belmont Report* (1979) placed "respect for persons" as the first of three central principles for dealing with human subjects research. The notion of respect for persons enshrined in the Belmont report explicitly discussed the link between respecting autonomy and respecting persons: respecting persons requires respecting their right to autonomy, understood as the right to make choices based on their own values, beliefs, and preferences (Lysaught, 2003, pp. 668-673). Less than a year later, the first edition of the famous *Principles of Biomedical Ethics* (Beauchamp & Childress, 1979) was published. The *Principles* was one of the first texts to formalize the core ethical principles of the nascent field of bioethics, and give it a distinctly philosophical bent (Lysaught, 2004, p. 674). The *Principles* replaced the principle of respect for persons with the principle of respect for autonomy. The principle of respect for autonomy became "first among equals," a place it continues to hold in much of bioethics (Jennings, 2009, 73).

Respect for persons survived this displacement, becoming a particular aspect of respect for autonomy. Respect for autonomy and respect for persons are not perfectly concurrent terms, but they largely overlap: According to the *Principles* "in evaluating the self-regarding actions of others we ought to respect them as persons with the same right to their judgments as we have to our own. This aspect of the principle of autonomy is often referred to as the principle of respect for persons" (Beauchamp & Childress, 2013, p. 59). Expanding on this, Beauchamp and Childress explain, "to respect autonomous agents is to acknowledge their right to hold views, make choices, and to take actions based on their values and beliefs" (2013, p.106). This notion of respect for persons *qua* autonomous agents reflects both its Kantian and Millian heritage, and has become one of the fundamental moral concepts in contemporary biomedical ethics.<sup>5</sup> In this understanding, preferences hold an important role in discharging obligations to respect persons and their autonomy: as far as patient preferences are assumed to

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<sup>5</sup> This notion is of course not limited to (bio)ethics. Political philosophy often also relies on the notion of respect for persons, although it is not always understood as respect for persons *qua* autonomous agents. Rawls, for example, takes a much more classically Kantian approach, and focuses on "respect for persons...[as] a recognition of their inherent worth and dignity" (Rawls, 1971/1999, p. 513). My focus here is primarily on the notion of respect for persons as it has developed in bioethics/healthcare ethics, and the particular way in which these fields have developed the notion. I leave aside any uses of the term in other areas of philosophy.

be a reflection of their judgments, evaluations, values, and beliefs, respecting patients as persons in clinical medicine requires respecting their preferences.<sup>6</sup>

However, when dealing with healthcare ethics, not just clinical ethics, we need to deal with many patients – often, the entire population of a country. The classical clinical version of respect for persons still stands in individual clinical encounters, but it takes on a slightly different form in attempts to respect autonomy on the scale of population level decisions, like healthcare priority setting. What this understanding of respect for persons reveals is a respect for the judgments (and resulting preferences) of the public – or rather, of a representative sample of the public. This notion of respect for persons (or respect for autonomy) is one of the primary motivations for the movement to include the public in setting priorities and establishing values for public health systems.<sup>7</sup> The way that respect for persons manifests on the scale required by healthcare ethics is taking account of and acting on the values of the population subject to these priority-setting (and other) decisions. This requires eliciting the preferences of the general public, and relying on their values rather than the values of those conducting the elicitations.

This is the sense of respect for persons that motivates the use of public preferences in eliciting health states. Health economist Alan Williams – often considered the founder of QALY, and a major proponent of QALY-style approaches to priority setting in health care – identifies six major principles that guide what he calls “conventional medical ethics.” These principles include, among other things, an injunction to “respect the autonomy of the patient” (Williams, 1994, p. 830). Williams goes on to explain that “[health] economists should have no difficulty whatever in seeing their own work in the health care field as being directed

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<sup>6</sup> This idea, that respect for persons (*qua* respect for autonomy) has become centered on the notion of patient choices or patient preferences is widely discussed. Eric Cassell’s reflection on the changes in medical ethics from *The Belmont Report* to the present, for example, argues that “respect for persons has been redefined from overriding concern for the sick person (almost solely) to the right of the patient to choose independently from among all options” (Casell, 2000, p. 21).

<sup>7</sup> See for example, the Oregon healthcare prioritization experiment, for a much discussed case in direct public involvement in priority setting. Perry and Hotze 2011 is a good review of the Oregon experiment. More generally, this kind of approach can be considered a part of the “person-centered healthcare” movement. See for example Entwistle and Watt 2013, and Epstein and Peters 2009, for discussions of the role of preferences in person-centered healthcare. Additionally, the use of “citizens councils” by NICE can be considered a practical manifestation of this notion. See Littlejohn and Rawlins 2009.

towards the fulfillment of those same six ethical principles” (Williams, 1994, p. 831).

Williams cashes this out in the notion of relying on the values (read, health-state preferences)<sup>8</sup> of the public. Specifically, he argues that for health economists, “respecting the autonomy of the patient would be seen as referring to the need to have the patients’ values count rather than those of the practitioners” (Williams, 1994, p. 831). This is where preferences enter the account of ethical treatment of individuals in health economics decisions. To respect persons, (aggregated) individual public preferences should establish the values of health states.<sup>9</sup>

This notion of respect for persons is an often unexamined assumption at the base of preference-based methods for health valuations like QALY.<sup>10</sup> As the methods of health economics have become increasingly integral parts of contemporary healthcare systems, there has been less attention paid to some of the fundamental justifications of the approach, such as those offered by Williams in the early years of popularizing QALY. In this thesis, I attempt to help fill this gap, and examine one of these justifications. Examining this justification requires answering the question: Does relying on health state preferences show respect for persons? In the next section, I explore this question: does respecting preferences respect persons? This answer to this question will determine whether QALY (and other similar public preference-based methods) live up to their ethical justification.

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<sup>8</sup> Remember, as discussed earlier, a fundamental assumption of all preference-based approaches to health valuation is that all value can be expressed in terms of preferences. So when health economists talk about the value the public places on something, the subtext is that this value can be expressed in preferences. So, public value in this context is equivalent to public preferences.

<sup>9</sup> There is a further question here: whether respecting aggregated public preferences is really the same as respecting individual preferences. Williams believes so, as he sees the use of population sampling and aggregation to establish these preferences as representing respect for persons. In his terms, relying on the “median values” of group to represent the appropriate value of a particular health state mimics “a system of group decision-making in which a simple majority is decisive” (Williams, 1994, p. 840). This results in an “ethical implication... that this is implicitly regarded as the ethically appropriate manner by which to come to a group value” (Williams 1994 p. 840). I won’t address the strength of this claim, I’ll instead assume that it’s true that population sampling really is an appropriate way to come to group value. The question I’ll address is focused on the use of preferences themselves.

<sup>10</sup> Notably, this underlying respect for persons not only motivates the use of preferences to establish health state values, but it also motivates various debates about distribution and age weighting, two other major ethical discussions in the use of QALYs.

### 3.) Does respect for health state preferences show respect for persons?

In this section, I argue that one of the primary ethical motivations for eliciting health state preferences – respect for persons – is not achieved by preference elicitation. I argue that if the state shows respect for persons by respecting autonomous preferences, and *only* their autonomous preferences, then the state does not show respect for persons through eliciting (non-autonomous) health-state preferences. This section has two primary aims: first, to establish that the state respects persons by respecting their autonomous preferences, and only their autonomous preferences (Sections 3.1-3.2). Second, to argue that health state preferences are not autonomous, due to problems with the process of affective forecasting, the process by which health state preferences develop.

#### 3.1) Should the state support individual preferences?

In this section, I canvas an argument from Mikhail Valdman that the state should support autonomous preferences, and *only* autonomous preferences. Then I develop an account of autonomy competence, and critically evaluate health-state preferences in light of this notion. I conclude by arguing that health state preferences are not autonomous in the relevant sense, and so there is no *prima facie* obligation for the state to support them. This in turn signals that eliciting health state preferences is not actually respecting persons.

It's commonly thought that the state has an obligation to respect persons. This is especially prominent in healthcare ethics, where respect for persons is a fundamental value. Further, in political philosophy, it is often accepted that the state has a *prima facie* obligation to pursue policies that have popular support. Mikhail Valdman asks about the connection between these two things: "Does an obligation to respect persons as such entail an obligation to respect people's preferences?" (Valdman, 2007, p. 21). Valdman ultimately argues that showing respect for persons does indeed require the state to respect autonomous preferences (and only autonomous preferences).

Valdman argues that a duty to respect persons entails a duty to "respect that which is connected or attached to persons in a certain way" (Valdman, 2007, p. 32). Although all of our preferences are attached to us in some sense, not all are attached to us in the way required to entail respect. To draw out the difference, Valdman distinguishes between being the mere 'bearer' of a preference and being the 'owner' of a preference. When someone is merely a

bearer of a preference, the preference is his or hers in a superficial sense. Preferences that have not been actively cultivated and endorsed, such as innate preferences, addictions, and non-conscious preferences all fall into this category (Valdman, 2007, p. 32). They are attached to us, but they are not really ours. In contrast are preferences that an agent has actively engaged with in such a way as to make them her own. When one has cultivated, maintained, and identified with a preference, one becomes the owner of that preference. This second set – owned preferences – are good candidates for autonomous preferences, a topic I’ll return to in the next section.

I find Valdman’s account compelling. It seems to me that he is right that respecting persons does require respecting some of their attachments, namely those that are actively and autonomously developed. In Valdman’s terms, we should show respect for attachments that an agent “has formed, and not to the attachments that he merely happens to have” (Valdman, 2007, p. 35). As a result of these attachments, the person-based respect we have towards an agent also extends to her autonomous preferences. Although I think Valdman is correct, I don’t intend to spend much time defending his account. I’ll assume he’s right that respect for persons requires respecting persons’ autonomous preferences (and only their autonomous preferences). In this section I canvassed an argument from Mikhail Valdman that suggests respect for persons only appropriately applies to autonomous preferences. In the next section, I address the question: “Are health state preferences (generally) autonomous?”

### 3.2) Are health state preferences autonomous?

Previously, I explained that respect for persons requires respecting persons’ autonomous preferences. Now I’ll explain what makes a preference autonomous. I base my notion of an autonomous preference on Diana Meyers’ concept of *autonomy competency*. In this section, first I explain what autonomy competency is. To clarify, in this thesis, I’m not concerned with evaluating the autonomy of respondents generally. I’m only interested in the autonomy of their preferences. And because people generally do not have cardinal preference rankings of health states prior to these scoring exercises, we need to examine the process by which they come to have these preferences – the process of decision-making about health state preferences. Focusing on the process of decision-making (as opposed to personal autonomy as a whole) also fits better with the dominant conceptions of respect for autonomy in bioethics,

which has typically held autonomous choice as central to respect for persons. After explaining autonomy competency, I argue that health state preferences fail to meet the requirements of autonomy competency. As I will show, there are in fact a wide variety of factors inhibiting some of the key competencies of autonomy, and resulting in the development of non-autonomous preferences. This in turn signals the failure of the ethical view of preference-based methods for valuing health.

In short, I'll argue that in light of this notion of autonomy competence, autonomous decision-making requires appropriately evaluating the options available to oneself, while taking into consideration one's (possible) life plans and current self-understanding. I'll explain affective forecasting, the process by which informants develop their preferences. I'll then argue that the problems of affective forecasting seriously impede informant's abilities to accurately assess the impacts of impaired health on their possible life plans, and so present a problem for the ethical view.

### 3.3) Autonomy in bioethics

Although autonomy is a central notion in bioethics and philosophy of healthcare, it is a hotly contested and relatively unsettled concept. There are a wide variety of views on what autonomy is, and an accompanying wide variety of views on what autonomous decision-making is. Part of the particular challenge in dealing with autonomy in healthcare is that ethical attention has often focused on the actions of physicians, and not on the actual decision-making processes of the patient. This is manifested in the predominance of the notion of informed consent, and accompanying accounts of bioethical autonomy focusing on simple freedom from coercion. However, in health state valuations, the only relevant concerns are the decision-making processes of the patient(s). Nothing (for the patients anyway) directly follows from their decision in the way it does in the classical clinical encounter. So, what is needed is a notion of autonomy not focused on autonomous choice as simply lack of coercion, but instead on the notion of autonomous decision-making. What does it mean for patients to make decisions "autonomously?"

As cliché as it may be to start with etymology, the most basic sense of autonomy is suggested by its etymology (*auto* – self, and *nomos* – rule). This basic notion of autonomy suggests that autonomous agents are those that can govern or rule themselves – establishing

their own goals, and selecting the methods for achieving those goals. This is in contrast to its opposite, *heteronomy*, or rule by another. But when we talk about ‘ruling over ourselves’ what is it really that we are doing? Usually, the thought is that we (in some relevant sense) are capable of choosing our life plans, and enacting them in line with our values, desires, and conceptions of the good. This notion – that some sort of life plan is required for personal autonomy – is a common one and is endorsed by a wide variety of accounts of personal autonomy (cf. Raz 1986, Colburn 2011, Meyers 1989, etc.). What is most important for my considerations here, however, is the *development* of an agent’s life plan, as this is ultimately what informants must evaluate when considering how to value health states.

Life plans are formed through a variety of processes, but what is especially important is the combination of memory, imagination, and practical reason that result in an agent’s ability to conceive of the various possibilities for life they could pursue, and the ability to assess and evaluate these alternatives in relation to their “true” or “authentic” self, however defined. In light of this, I rely primarily on Diana Meyers’ account of autonomy, as it focuses both on these aspects as well as on the notion of autonomous decision-making. Further, the notion of autonomy competency also nicely mirrors the notion of evaluative competency that underwrites the evidential view. Although I rely on Meyers to explicate my argument, I intend the view of autonomy put forward here to be compatible with any account of autonomy that recognizes the need for imagination, evaluation, and some notion of a life plan.

In the next section, I briefly explain the relevant aspects of Meyers’ account of autonomy competency, before turning to an examination of the problems in the process of affective forecasting, and the consequences these have for the assumption of autonomy competency.

### 3.4) Autonomy competency

When it comes to health state valuations, we are interested in how autonomous decisions are made, in the processes and procedures informants follow or fail to follow. This requires understanding autonomy not as some special sense of free will, but as a set of key skills, the competent exercise of which results in autonomy. Diana Meyers develops an account of autonomy along these lines, arguing that “autonomous people must be disposed to consult their selves, and they must be equipped to do so. More specifically, they must be able

to pose and answer the question “What do I really want, need, care about, value, et cetera?”; they must be able to act on the answer; and they must be able to correct themselves when they get the answer wrong. The skills that enable people to make this inquiry and to carry out their decision constitute what I shall call *autonomy competency*” (Meyers, 1989, pp. 52-53). In short, Meyers’ account requires agents to be able to formulate life plans in response to their “capabilities, inclinations, and feelings,” and to carry out these plans. (Meyers, 1989, pp. 46-49).

These skills are important because they capture what is central about autonomy competency for health state valuations: the relationship between an agent’s self-understanding and their possible life plans. Fundamentally, the process of valuing a health state is the process of imagining and evaluating possible future life plans. Informants are not asked for baseless speculation about the value of health state. Rather, they are supposed to consider the options presented by a TTO/SG valuation exercise in relation to the things that matter to them – their values, desires, goals, and plans, and how these would be impacted by impaired health. Doing so requires informants to imagine the possible lives they could lead with the impaired health state in question. They need to be able to evaluate it in relation to their current life plan, as well as other possible life plans that may suit them. This puts life plans and the ability to imagine and appraise them at the center of informants’ valuation procedures.

This fundamental component of health state valuations is also a core competency for autonomy. A key component of autonomy is an agent’s ability to conceive of and appraise possible life plans. Agents must envision and evaluate combinations of traits and characteristics they could embody, and aims or goals they could pursue – rough schemas of things to do and be (Meyers, 1989, pp. 52-53). An autonomous person is able to envisage these schemas, and evaluate them in relation to their concept of themselves. In other words, an autonomous person is one with a sure sense of their identity, and the ability to plan their life in relation to their identity (Meyers, 1989, p. 84). If an agent’s ability to formulate life plan(s) in relation to their identity is impaired, their autonomy is impaired as well. Psychological disorders, for example, may preclude an agent’s ability to craft an actionable life plan that is appropriately sensitive to oneself. Likewise, an agent being blind to his or her own self (that is, lacking competence in self-discovery) may result in a lack of autonomy (Meyers, 1989, p. 84).

Crucial to a full account of autonomy is the ability to act on this combination of life plan and self-definition, but for my purposes here, an agent's abilities to act are secondary. Health state valuations are primarily imaginative, not active, endeavors. There seems to be no reason to assume that informants have any trouble knowing themselves, or being sure in their identities. It is certainly the case that some informants will have a clearer understanding of themselves than others, but as far as I can tell, there is nothing the process of valuing health states that would obscure or otherwise undermine informants' abilities to know themselves. Instead, it seems like the main challenge for autonomy will be how informants imagine and appraise possible life plans.

So, the question for autonomy is about informants' abilities to plan their lives in response to the health valuation exercise they are given. As I will explain, the problem is that informants are poor predictors of how health states impact their lives. In other words, their capacities to envisage and evaluate their life plans are limited and often distorted. This is because a variety of biases and heuristics undermine agents' abilities to adequately imagine and appraise the impacts of impaired health on their life plans. This is a problem for the brief account of autonomous decision-making sketched above, which requires the competent evaluation of possible life plans. Next, I'll examine some of these biases and heuristics that undermine autonomous decision-making in health state valuations.

### 3.5) The problems with affective forecasting

The process of valuing health requires the use of *affective forecasting*. In the context of this thesis, affective forecasting is the prediction of how various health states will impact well-being. The problem with affective forecasting is that people are bad at it; they severely overestimate the negative effects that changes in their health status will have on their well-being. A particularly striking example is how those disabled after serious accidents and those who have recently won the lottery both end up with about the same level of (self-reported) well-being about six months after the event (Brickman et al., 1978). The reason for this counterintuitive result is known as *adaptation* (sometimes called "hedonic adaptation"). An overwhelming amount of evidence indicates that people adapt to their circumstances after a brief transition period, and their well-being reflects this adaptation: Impaired health does not have as severe of an effect on quality of life as *ex ante* informants typically assume. This is not

limited to paraplegia: this gap has been demonstrated for visual impairment, asthma, dialysis, heart disease, and colostomies, among others (Halpern & Arnold, 2008, p. 1708). Although this process of adaptation seems to occur in almost every form of health impairment, people are generally unable to predict the fact of adaptation, and have trouble incorporating it into their judgments about future quality of life (Dolan & Kahneman, 2009, p. 227; Wilson & Gilbert, 2005, p. 132). In all, this results in overly severe evaluations of future quality of life.

The fact of adaptation is a serious methodological difficulty for the use of preference-based methods to value health. But it is not the only problem: there are a number of “cognitive illusions” that influence individuals’ judgments as well. One well-known case is the problem of *framing effects*: people develop very different preferences depending on how the case description of a health state is worded (Hausman, 2015, p. 102). There is also evidence that otherwise irrelevant features of our surroundings can subtly influence our preferences: one study reveals that informants who find a coin prior to scoring health states provide higher scorings than those who did not find a coin (Hausman, 2015, p. 110). The coin study is just part of a broader set of studies that indicate that informants’ predictions of future quality of life depend heavily on whether they are in a positive or negative mood at the time of evaluation (Halpern & Arnold, 2008, p. 1710). In short, irrelevant aspects of the question-asking and decision-making processes influence informants’ health valuations.

Further, informants’ decisions suffer from a problem known as *focalism* or *focusing effects*. Put broadly, focalism is a narrow focus on what will change as a result of impaired health, while ignoring the fact that much of one’s daily life, and the activities one enjoys, will remain unchanged (Dolan & Kahneman, 2008, pp. 223-224; Ubel et al., 2001, p. 191; Wilson & Gilbert, 2005, p. 132; Wilson et al., 2000, p. 823; Halpern & Arnold, 2008, p. 1709). Informants tend to focus only on a narrow range of activities and options that are directly connected to their impaired health, and ignore the rest of their life that goes unchanged. Further, these effects are durable; ‘defocusing exercises’ designed to combat focusing effects seem to fail in medical contexts (Ubel et al., 2001, p. 197; Ubel et al., 2005, p. S62). In all, informants ignore the full context of their lives, and only pay attention to the narrow areas directly impacted by impaired health.

While there is evidence that these kinds of heuristics and biases are always with us, they are particularly prominent when we are under heavy cognitive load (e.g. tired, stressed,

multitasking, etc.) (Levy, 2012, p. 297). And there's good reason to think these kind of health state scorings are cognitively taxing activities. By their very nature, all-things-considered judgments about future quality of life in a particular health state are difficult and cognitively taxing activities. Furthermore, there is evidence that respondents are stressed or uncomfortable during this process. Respondents frequently express concern about their role in scoring health states, and express discomfort at having to perform these kinds of evaluations (Hausman, 2015, p. 89).

The above sampling is not exhaustive, but it is enough to illustrate the problem: these cognitive biases, illusions, and distortions pose serious challenges to the evidential view of scoring health states through preferences. The issues described above result in inaccurate and misleading values for health states. This is clearly an evidential problem. But my question has to do with autonomy: in so far as we assume that preference-based measures are supposed to reflect respect for persons, and as long as this respect for persons is shown through respecting autonomous preferences, we need to determine if these effects and biases are a problem for the development of autonomous preferences. How do these problems affect respondents' autonomous decision-making capabilities?

### 3.6) Imagination, evaluation, and the problems of affective forecasting

In this section, I explain how the aforementioned problems with affective forecasting undercut informants' autonomous decision-making capacities. In short, in the process of health state valuations, informants represent to themselves the possible kinds of lives they could live given the limitations of the impaired health state in question. By evaluating these possibilities in light of both their selves and their possible revised life plans, they put themselves in a position to make a decision. In this context, autonomous decisions are those that appropriately value the options available in light of an agent's possible life plans and self-understanding. Heuristics and biases in affective forecasting undermine this process of imagination and appraisal. As a result, the decisions made in TTO/SG valuing exercises are unlikely to be autonomous.

The general problem is that the failures of affective forecasting obscure the required complexity of informants' imaginative evaluations. Valuing health states requires a rich, complex, and cogent envisioning of one's life as altered by health impairment, and consequently, the resulting changes in one's life plan and self-understanding. Informants then

make their evaluations on this basis. Problems with affective forecasting undercut the complexity and richness required for valuation exercises to be a useful source of information and an adequate basis of evaluation for autonomous decision-making. This failure of imagination brought about by flaws in affective forecasting poses two interrelated problems. First, it deprives agents of important information. Second, it causes a flawed appraisal of their options. I argue that both of these present problems for autonomy because they result in a failure to appropriately value the options available in light of an agent's possible life plans and self-understanding.

First, as far as informants' imaginings of how these health state will affect them and their lives serve as a kind of information that they can base their decisions on, the problems of affective forecasting undermine the accuracy of this information. In a typical valuation exercise, some information is provided to the informant – namely, a case description of the health state in question. However, the informant is required to supply their own information – how they will fare under such a health state, and what it would be like for them to live with this kind of impaired health. This is exactly the information that is compromised by the problems with affective forecasting. This flawed information undermines the autonomy of informants' decision-making. It's commonly acknowledged that ignorance can pose a problem for autonomy. For an agent to be able to choose, first she must be aware of her options. To choose in an autonomous and authentic way, an agent must also be aware of the consequences of each possible choice, and the way these choices will impact her life going forward (Raz, 1986, p. 371). As a result, autonomy is compromised when an agent is unaware of her possible options, and chooses based on this incorrectly limited set (May, 1994, p. 134; Raz, 1986, p. 371). Informants have mistaken beliefs about what life would be like in a particular health state, owing to ignorance of the problem of adaptation and the distortions provided by other forecasting biases. In so far as they make their decisions about which option to prefer on the basis of these mistaken beliefs, they are making non-autonomous decisions.

The second problem is not just that informants may make their decisions on the basis of incorrect beliefs, but that they will fail to properly appreciate the options they have. This is not an issue of knowledge so much as it is of comprehension or appraisal. It is not enough that an informant simply has the required information; she also needs to be able to grasp its significance, and understand how it relates to her values, desires, and goals. Focalism, for

example, threatens an agent's ability to imagine and assess her future comprehensively, with enough breadth and detail to make an autonomous decision about her options. Instead of understanding the role that impaired health will actually play in her life, her understanding is skewed, and she believes it will play a major, perhaps defining, role in her future life.

Adaptation also plays a role here: an agent's inability to account for adaptation will prevent her from clearly imagining life with impaired health, and so she fails to properly appreciate the nature of the potential lives she could lead with such a health state. As a result, she fails to really evaluate the options available. In all, although informants may have all the relevant factual information, they can still fail to grasp the significance of this information for themselves and their own lives.

Further, this claim –that agents may fail to properly appraise the options available to them– is also supported by studies of how informants view their decisions weeks after the fact. As Hausman 2015 explains, some studies indicate that when re-interviewed weeks after the valuation exercise, informants' preferences had often changed. Informants explained that as they were able to think more deeply about their lives and the impact of impaired health, they came up with quite different evaluations than they had originally provided (Hausman, 2015, p. 88). This further supports my argument: In view of the profound impact of biases and heuristics on affective forecasting, it can no longer be simply assumed that informants' first impulses really reflect their "true" or "authentic" choices. Instead, a reflection of their true or authentic choices would only be revealed through a serious engagement with both the individual informant's self-definition and their over-arching possible life plans. Without this kind of engagement, the choices expressed by informants don't amount to autonomous decisions.

In short, the problems with affective forecasting are not just problems for determining the impact of health states on well-being, they also potentially pose a problem for autonomous decision-making. In so far as autonomous decision making requires agents to properly imagine and evaluate their options in light of both their possible future life plans and their self understandings, their autonomy is impaired by the problems with affective forecasting. They are impaired in at least two ways. First, the problems with affective forecasting result in informants making decisions on the basis of inaccurate information. Second, these problems undermine informants' abilities to appropriately value or appreciate their options. In both

cases, the imaginative and evaluative capacities informants depend on to make autonomous choices about their future are undermined, and as a result, so is the autonomy of their decisions. Hence, stated health preferences, so far as they are a reflection of this decision-making process, are not autonomous. In the next section (Section 4), I'll argue that this is a problem for the ethical view. But before that, I will address an objection to the argument given above.

### 3.7) Objection: does the argument go too far?

It may be objected that my criticism goes too far: not only are informants' decisions in health valuing exercises not autonomous, but it may seem like my argument undermines the autonomy of very many, or perhaps even all, of our decisions. I have two responses to this: first, that we should not reject empirical work on cognitive functions just to preserve the philosophical notion of autonomy – if our notion of autonomy is incompatible with solid evidence about how our mental faculties actually work, then we need to be attentive to that fact, and alter our accounts of autonomy accordingly.

Second, I don't believe the extreme skepticism about autonomy my argument may suggest is warranted. To start, we should keep in mind that the process of deciding between options in a TTO/SG scoring exercise is a very difficult and cognitively taxing process. Processes such as this make it more likely that the various problems associated with affective forecasting will play a large role. This particular context of decision-making is an unfamiliar and likely stressful one. Not all of our decisions occur in such a context, and so we need not think that these biases and distortions undermine all of our future-directed decisions. Further, these processes are usually somewhat time-limited: informants are expected to provide an answer within the timeframe of the valuation session. In contrast, if a decision like this were to be made 'in the real world,' individuals would likely take much more time to decide, consulting with friends, family, and their physician in making the decision. This fact – that the conditions of valuation exercises are non-ideal for autonomous decision making – helps to explain why we should be skeptical of informants' decisions in this area, but not necessarily skeptical of their decisions generally.

Moreover, there is often a lack of relevant knowledge and experience with the health conditions in question. It is true that health economists provide informants with case

descriptions of the health condition, but this is very different from when we have to make other kinds of decisions on the basis of future-welfare prediction. If we consider, for example, a young person deciding between careers (assuming they are making this decision on the basis of future welfare), they are often in a much better place to really appreciate and value the options available, and they are able to access far more (and more meaningful) information than their peers in the health valuing exercise.

However, the argument above does suggest skepticism about autonomy in similarly stressful and difficult circumstances – such as those that actual clinical patients find themselves in. The division of labor whereby patients provide the judgments about what’s best for themselves, while physicians provide only the basic information about treatment options, should be strongly rejected. If these kind of predictive distortions are a problem for autonomy – and I contend they are – then they may undermine patients’ abilities to make truly autonomous decisions about their medical care. The notion of respect for autonomy needs to be revised in light of the problems our mental faculties pose for the successful and competent exercise of autonomy. How this is done – whether by embracing paternalism, developing models of shared decision-making, or redefining autonomy – is not something I will adjudicate here. However, it should be taken as a serious problem, and as a valuable direction for future research.

The most important upshot of my argument here is actually not about health valuations themselves. Rather, it is about how we approach one of the central concepts of bioethics – autonomous choice. We should take seriously imagination as the basis for autonomous evaluation and decision-making. It is often the case that patients are not choosing between treatments with different levels of success, but rather between treatments with different consequences for quality of life. Patients (and in the case of valuing health, informants) are required to make difficult decisions on the basis of their predictions of future quality of life. These predictions are made largely on the basis of patients’ imaginative faculties. So, what is required from bioethics is a serious investigation into the role imagination plays in patient evaluations and patient decision-making. We have a number of key questions left open, the answers to which have serious consequences for our understanding of autonomy and respecting patient choices. Most pressing to my mind (and what I’ve dealt with here) is the question “What factors impede patients’ imagination and evaluation when it comes to making

their decisions?” As long as we require autonomy to have some kind of engagement with the notion of a life plan, and as long as we require patients to engage in predictive exercises about their future, we will need a stronger understanding of the role imagination plays and the factors which might undermine its successful exercise. Without such understanding, our notion of autonomy will be seriously flawed.

In this section, I’ve argued that the problems with affective forecasting undermine informants’ imaginative and evaluative capabilities, resulting in substantially non-autonomous decisions. In the next section, I explain the problem this proposes for preference-based health valuation methods.

#### 4.) Conclusion: a call for imagination in health economics and healthcare ethics

In this section, I’ll review my argument, and explain the consequences of this thesis. I address the consequences for both the process of establishing values for health states, and for healthcare ethics and health economics more broadly.

The ethical view holds that relying on public preferences is the appropriate choice for establishing health values, because it shows proper respect for persons (Section 2.2). However, I’ve argued that respecting persons requires respecting their autonomous preferences, and only their autonomous preferences (Section 3.1). Further, I’ve argued that health state preferences are not autonomous due to problems with affective forecasting (Section 3.5-3.6). Therefore, preference based methods of valuation, like those used to establish the QALY, do not show respect for persons, and so do not meet their proposed ethical justification (Section 3.2-3.6). In all, what this argument suggests is a problem for the ethical view: QALY and related measures do not actually have the kind of ethical justification as claimed. Now, this doesn’t mean they are unethical – it just means there may be one less reason to support them. My argument suggests that perhaps different valuation methods should be implemented, or that valuation exercises should be modified in order attempt to elicit autonomous judgments.

However, given the inherent difficulties with this kind of preference-based approach to health valuation, I am skeptical that these valuation exercises could be modified in such a way to be both representative of individuals’ autonomous decisions, and still be practically feasible. The amount of work required to make autonomous decisions on the basis of all-things-considered evaluations about one’s potential future welfare would be simply too much

to ask of informants. The possibility of implementing a different way to value health seems like a much stronger option. There have been recent attempts to value health on different bases, which do not rely on aggregated public preferences in the same way. Daniel Hausman, for example, has proposed a way to value health through its impacts on opportunity (Hausman, 2015, pp. 171-186). Jennifer Prah Ruger (2010) has attempted to develop a measure based on a version of the capabilities approach. In both cases, they avoid the problem presented in this thesis, because they provide a different ethical justification than the principle of respect for persons. Hausman supports his approach by an examination of the fundamental role of opportunity in liberal democracies, while Prah Ruger's capabilities approach holds these capabilities to be a kind of fundamental entitlement. Neither of these approaches requires establishing a tenuous (and I hope to have shown, false) relationship between respecting persons and establishing health values through public preferences.

However, there is a third possibility. There is also the possibility to drop the claim that this area of health economics has anything to do with respecting persons, and instead stick to justifying it solely on evidential grounds. I suspect this last possibility is the most likely outcome, given the major role QALY plays in health economics, and the relatively little attention given to the notion of respect for persons when considering the ethical aspects of health valuation exercises. The problem with this route is that it places all of the justificatory weight on the evidential view, a view that has been severely and thoroughly criticized (For example, Hausman 2015). If preference based measures like QALY are not well supported evidentially, and there are no ethical reasons counting in their favor, then their justification may seem rather weak. This in turn again suggests that a shift towards opportunity or capability-based approaches would be a valuable move for health economics.

So far, I've described the direct consequences of my thesis for preference-based approaches to valuing health. However, there is another broader and more important upshot of this argument. What my examination of autonomous decision making reveals is a need for health economics and healthcare ethics to focus on the role imagination plays in the processes of decision-making. I've argued that we should doubt whether the preferences expressed in TTO/SG valuation exercises are autonomous. My argument relies on the fact that certain problems in the process of affective forecasting undermine informants' abilities to adequately imagine and evaluate possible life plans, a central component of autonomous decision-making.

The consequences of this argument go beyond solely how we value health states. It potentially applies anywhere that individuals have to make decisions, and have to make decisions where autonomy is important. The upshot of this is not, as the objection in the previous section claimed, that we should regard all of our decisions as non-autonomous. Rather, it is that we need greater philosophical attention on the processes of individual decision-making in both health economics and healthcare ethics. And what this attention on decision-making requires is a thorough investigation of imagination and the role it plays in decision-making.

I hope that my focus on the context of valuing health states, which is a fully hypothetical and imaginative exercise, has made the role of imagination especially clear. But the role of imagination applies equally well to ‘real’ cases of patient decision making. Though patients are not asked to make a trade-off between some years in perfect health and some greater number of years in impaired health, they are frequently required to make decisions on the basis of (predicted) quality of life alone. Often, the main differences between treatment options are the differences in impact on quality of life. In these cases, patients’ imaginative and evaluative capabilities should be at the forefront of our concerns. As long as patients have to make decisions on the basis of their own prudential judgments, their imagination will play a central role in their decisions.

Although there has been significant work done in imagination in many other areas of philosophy (and of course, extensive work in psychology and cognitive science), imagination has not received the same level of attention in bioethics and health economics. I’d like to suggest that this is a severe omission, and I hope my thesis has helped to illustrate why.

## Summary/Abstract

Health is often valued by its contribution to well-being. The most common way to establish values for health states is through eliciting a sample population's preferences among states. The *evidential view* supports preferences based on the idea that preferences provide reliable indicators of well-being. The *ethical view* takes eliciting preferences to show proper respect for persons. I address the ethical view. In this thesis, I explain the process of valuing health states and describe the evidential and ethical views. I explain how preference-based measures are supposed to show respect for persons, and that respect for persons is shown by respecting autonomous preferences, and *only* autonomous preferences. I argue that health state preferences are not autonomous preferences, and as a result, preference-based measures do not show respect for persons. Thus, they are not actually supported by the ethical view. I explain the consequences of this argument for health valuation, suggesting that this gives us a reason to prefer methods that value health on other bases, e.g. through opportunity or capability. I also suggest that this has consequences for how we should think about autonomous choice in healthcare, and propose that bioethics needs further investigation into the processes of patient decision-making.

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