

Penultimate draft of: Dan Brock (2014): Reflections on the Patient Preference Predictor. *Journal of Medicine and Philosophy* 39(2), 153-160. For the final version, please contact the author (dan_brock@hms.harvard.edu) or go to the *Journal of Medicine and Philosophy* website (<http://jmp.oxfordjournals.org/>).

Reflections on the *Patient Preference Predictor* Proposal

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Abstract: There is substantial data establishing that surrogates are often mistaken in predicting what treatments incompetent patients would have wanted, and supplements such as advance directives have not resulted in significant improvements. Rid and Wendler's Patient Preference Predictor (PPP) proposal will attempt to gather data about what similar patients would prefer in a variety of treatment choices. It accepts the usual goal of patient autonomy and the Substituted Judgment principle for surrogate decisions. I provide reasons to question sole reliance on autonomy when surrogates, not patients, are deciding, and for giving some independent weight to patient well-being. Moreover, that family members, typical surrogates, will know best what the patient if incompetent would have wanted is not the only reason why they are chosen. The more serious problem is that the PPP would fail to remove the more serious mistakes that empirical psychology over the last few decades has shown infect such decision making.

It has been well known for some time that surrogates are relatively poor predictors of incompetent patients' treatment preferences. Some of the data establishing this is summarized and cited in Rid and Wendler's papers in this issue of the *Journal of Medicine and Philosophy* (Rid and Wendler 2014a, Rid and Wendler 2014b). That was one of the issues that led Allan Buchanan and me to write *Deciding for Others* (Buchanan and Brock, 1989) now nearly 25 years ago. As Rid and Wendler point out, there has been little progress in improving surrogate decision making since then. It remains the case that most patients still do not have advance directives to help guide surrogate decision makers deciding for them should they be or become unable to make those decisions for themselves. Moreover, as demonstrated in the Support Study, physicians frequently pay little attention to patients' advance directives when they do exist and are made available to them, and the advance directives are usually not helpful in guiding the decisions that arise and must be made. (Teno 1998) It has now become clear that advance directives are a very limited solution, at best, to the problem of surrogate decision making. Other possible solutions such as encouraging discussions between persons/patients, while competent, and their potential surrogates about their treatment preferences in likely future circumstances, to the extent these are predictable, have also not significantly improved surrogates' accuracy in predicting incompetent patients' preferences. Yet

what we called the Substituted Judgment Principle 25 years ago remains the consensus guidance principle for surrogates to follow: use whatever relevant knowledge you have about the patient and his/her values and desires to make the decision he/she would have made in the circumstances if he/she were competent. This reflects the increasingly prominent role given to patient autonomy in health care decision making generally over the last half century.

So what is to be done? Should we just accept that we have failed to improve the quality and success of surrogate decision making? To Rid and Wendler's credit, they are not ready to give up, but instead have made a serious proposal to improve surrogates' decisions. Their Patient Preference Predictor (PPP) will attempt to gather data about what similar patients would prefer in a variety of treatment choices. It is of course unknown how much more accurate surrogates' decisions would be if their proposal were implemented, although evidence suggests some more. That is important if only because implementing it would involve substantial costs and efforts, which would only be justified by significant improvements in surrogate decision making. I shall assume that there would actually be some significant improvement in the accuracy of surrogates' predictions of their incompetent patients' wishes in order to pursue some other questions about their proposal.

Respecting Autonomy as the Goal of Surrogate Decision Making

Autonomy is most clearly and fully realized when a competent patient makes an informed and voluntary treatment decision reflecting his/her own relevant values. This will also usually, although certainly not always, be a decision that best serves the patient's interests or well-being. These two values of autonomy and well-being are usually not in conflict, but sometimes they are. This is important because the substituted judgment standard for surrogate decisions aims to promote only the value of autonomy, even in instances when doing so may not best promote the patient's well-being. In the case of a competent patient, ethics, public policy and the law, with only a few exceptions such as public health threats, all accept that a competent patient's choices among available treatments (costs may reasonably limit the availability of treatments) must be respected. Only if the patient is deemed incompetent may a surrogate be empowered to make the decision and to possibly make a different choice. This raises the question of whether autonomy should also be the only value guiding surrogate decisions for incompetent patients. The answer to this question is not uncontroversial. People's interest in autonomy is the interest in making important decisions about their lives for themselves and according to their own values or conception of a good life. There are two components in this one sentence account of autonomy: people making important decisions about their lives for themselves; according to their own values or conception of a good life. In cases in which we turn to surrogate decision making, the first component cannot be realized—that is why we turn to a surrogate. The second component can only be indirectly realized by surrogates attempting to use their understanding of the patient's values or conception of a good life to guide their decision, and as we have seen above they often fail in their attempt to do so. So in surrogate decision making autonomy can only be partially and indirectly, at best, achieved. This suggests that perhaps autonomy should not be given the sole weight in surrogate decision making that it is given in decision making by a competent patient. Likewise, the patient's well-being might be given proportionately more weight when it conflicts with the result of substituted judgment. The relevance of this for the PPP project is that we might be less concerned with surrogates' failures to predict correctly what the patient would have chosen, at least when the surrogate's decision better conforms to the patient's well-being. This could give us reason to reconsider the substituted judgment principle which promotes only the attenuated autonomy of the

incompetent patient without considering his/her well-being, as well as to be less concerned about surrogates' predictive failures. (I return to this below.) Nevertheless, at least for now substituted judgment remains the consensus standard in medicine, bioethics, and the law, and this is what motivates the PPP proposal to enable surrogates' decisions to do a better job of meeting that standard.

What are the Reasons for Patients' Choices of a Surrogate?

There is another reason to be less disturbed about the relatively high rate of failure of surrogates to predict their incompetent patients' wishes. It is that the ability to do so is typically not the only reason that patients choose a close family member to be their surrogate, or would choose them if they were able to do so, although Rid and Wendler cite evidence that it is the usual reason. (Brock 1992) In many cases it may not even be the most important reason for their choice of surrogate. Families constitute social units in which very close relations typically develop over time among their members. Family members typically develop intimate knowledge of the other family members, which is of course one reason for common beliefs that a family member may be best able to know what you would have wanted should you become incompetent to decide for yourself. But families are also where strong feelings of love and responsibility for other members develop. When people are in need of help of various sorts from others, it is to other family members that they will typically first turn. This may be for many reasons, but at least one important reason is that in well-functioning families its members feel a responsibility to help and care for other members. And it is not just that they have these feelings. In nearly all societies, the family is a social unit in which substantial responsibility for its members is assigned. This is most obvious in the case of children, but it holds for adult members as well. It is commonly family members who make decisions about when debilitated members must move to various kinds of care facilities. Social norms in this area are changing and the degree to which families are deemed responsible for elderly members no longer able to care for themselves is probably declining in many societies, but families remain the primary caregivers for elderly incompetent members. With these obligations and responsibilities must come some discretion in how the obligations are discharged. Norms within communities even more than the law assign major caregiving responsibilities to families. This means that there is typically a strong expectation, both among those in need of care and family members who could provide it, that the family members will in fact do so. To do so they must have some significant discretion in what and how care will be provided. So it will not always be subject to a strict substituted judgment standard—what would the incompetent person want, without regard to the impact on the family members and others providing the care. Instead, it will often be a complex negotiation among all involved and affected.

PPP and Autonomy

I have offered above the reasons to think that the selection, evaluation, and authority of surrogates does and should not depend solely on how well they are able accurately to predict an incompetent patient's wishes and preferences about care. Nevertheless, improving that prediction is the aim of Rid and Wendler's PPP proposal. Need providing the information about what other persons relevantly like the patient in question would want in similar circumstances in any way undermine the autonomy interests of the patient or his/her surrogate? I think not. Assume first that this is simply information provided to the surrogate, but that it remains up to the surrogate what weight, if any, to give to the information. Other information standardly given to the surrogate will be the physician's recommendation about care and the reasons for that recommendation. The physician's recommendation will sometimes, perhaps often, come

with subtle or not so subtle pressure to accept that recommendation. This also need not conflict with respecting patients' or their surrogates' authority as decision makers. Even with competent patients, the more patients seem to be making treatment choices strongly contrary to their best interests, the more their physicians should and typically do strongly advocate for what they believe would instead be in their interests. This advocacy should be done in a manner that makes clear that the decision is theirs to make, but it is part of carrying out physicians' commitment to their patients' well-being. Making treatment recommendations, and explaining and defending them, in no way need compromise competent patients' autonomy and authority. I think the same is true in the case of surrogate decision makers. There the physician may have reasons to be uncertain or skeptical about whether the surrogate is accurately representing the patient's wishes, which would presumably not be the case when a competent patient is deciding for him/herself. So the physician's role and responsibility as advocate for the patient's well-being can be even stronger when working with a surrogate for an incompetent patient.

Competent patients' treatment choices are also often challenged by family members or friends, not just by their physicians. So long as these challenges are not coercive they do not compromise the patient's autonomy or their authority to make the decision. Instead, they are a reflection of typical concern of the family members or friends for the patient's well-being. Most of us would want others close to us to express that concern when they believe we are making important decisions about our lives which are seriously contrary to our best interests. This too is a common and desirable feature of social life and need be no challenge to our autonomy or authority to make the decisions in question.

The information that the PPP would provide to a surrogate about what other similar patients would want is not unlike what the physician provides to the surrogate. The physician provides his/her judgment about what treatment would be best for this patient in the circumstances. That judgment will inevitably be influenced by his/her experience with other patients facing similar treatment choices—both by what those other patients have chosen, as well as by whether they were satisfied with their choices after the fact. This is not unlike the information that PPP would provide both the physician and the surrogate. Rid and Wendler do not indicate whether PPP would provide this second sort of information about whether actual patients were satisfied with their choices after the fact. This information would not be available when the decision leads to death or in cases of permanent decisional incapacity, but it would certainly be important information when it could be available. The reason is that there is growing evidence that individuals make important systematic mistakes in decisions like those about treatments.(Kahneman 2011; Gilbert 2006). Surveys like those envisaged by the PPP project are likely to replicate rather than correct for those mistakes. Rid and Wendler do envisage giving individuals participating in the PPP surveys information about these mistakes, but it is unclear how much that would eliminate their influence in the surveys. I believe these decision mistakes are a serious problem for the PPP project, but also a serious wider problem for the weight currently given to patient autonomy in treatment decisions by competent patients as well as by the substitute judgment principle as the guide for surrogate decision makers.

Common Decision Making Mistakes

What are examples of some of these common and systematic mistakes? First, predicting how good or bad future outcomes will be, in particular how good or bad one will find them when they in fact are experienced. The general finding from empirical psychology is that in the case of a bad outcome people predict that it will be much worse than they in fact find it to be when it in fact occurs. Likewise, in the

case of a good outcome, they predict that it will be much better, will have a bigger positive effect on their subjective well-being, than it in fact does. Brickman, Coates, and Janoff-Burman (1978) found that lottery winners were less happy in comparison with a control group than would have been expected, and that victims of accidents that left them paraplegic or quadriplegic were less unhappy with their condition in comparison with a control group than would have been expected. The explanation for this result is controversial; it is often referred to as a treadmill effect. After a significant positive or negative event, people tend to return to their baseline level of happiness. It is also a feature of adaptation where people have failed to take account of their ability to adapt to either a positive or negative change in their circumstances. This shows up as well in measures of subjective well-being in various states of disability, such as the Health Utility Index. (Horsman 2003) If people are asked on a zero to one scale how bad it would be to be in various states of disability such as blindness or paraplegia, persons not in those states rate it as significantly worse than do persons actually in those states. Here again, the most prominent explanation seems to be a failure to take account of adaptation. (Menzel 2002) The responses obtained in the PPP project are likely to suffer from the same deficiency.

Systematic mistakes arise in recalling past experiences as well as predicting how good or bad future ones would be. In another famous experiment, patients who were to undergo a colonoscopy were divided into two groups, both of which would be conscious and so experiencing significant discomfort during the colonoscopy. (Kahneman 2011, 379-381) The first group had the standard procedure. The second group differed only in that instead of withdrawing the scope at the end of the procedure, as with the first group, the scope was left in for an additional few minutes without moving it and then withdrawn. There was still significant pain or discomfort when the scope remained inserted but not moving, but much less than when the scope was moving. The two groups were then asked how bad the procedures were and the first group found it significantly worse. But they differed from the second group only in that they did not have the few minutes of additional milder pain that the second group had. So how could their experience, shorter and with less pain, have been worse? The explanation was put down to two phenomena that have been replicated in many other contexts and experiments. In evaluating past experiences, people tend to focus on the peak and endpoint, but to ignore duration. So here, the peak, how bad it was at its worst, was the same, but the end point for the first group was worse because it involved the pain of the moving scope, whereas the endpoint for the second group involved a less painful stationary scope; duration of the pain was essentially ignored. So the group that differed only in experiencing less pain judged it worse. This is only one example of various heuristics that people use in decision making that appear to lead them to mistakes. There are many other examples, such as those in dealing with probabilities that also lead to mistakes, and probabilities are of course of great importance in medical treatment decision making. So far as I can see the results of the PPP project of collecting people's preferences in various typical medical treatment decisions would be shot through with these various mistakes.

Now as I have already emphasized, this is not a special problem for the PPP project. These various mistakes equally infect the decisions of competent patients. And since we accept the decisions of competent patients, "warts and all," perhaps this is not a serious problem for the PPP project. But I am less sanguine that it can be dismissed so easily. The current emphasis on patient autonomy and shared decision making replaced a paternalism that saw physicians as the expert decision makers and largely left patients out of the process. As treatment options increased in much medical decision making, it was recognized that there was often no single answer that would be right for all patients independent of the values of the particular patient whose decision it was. There is no reason to return to that older

paternalism, and it would probably not be possible in any case. Among other things, physicians are probably equally subject to most of these decision making problems as patients. That older paternalism began to be displaced before much of the work in psychology displaying the heuristics and the mistakes they lead to was done, certainly before it reached the level and depth it now has. But my principal worry about the PPP project is that it will largely just reproduce those difficulties. Even if it may lead to decisions that better match up with patients' preferences, it will do little if anything to remedy the increasingly obvious difficulties in those preferences. I think the much more daunting task before us is to try to reconceive shared treatment decision making, both for competent and incompetent patients, in a way that better reflects and remedies the depth and breadth of the difficulties we now know infect patients' and their surrogates' decision making. I'm not sure how this can be done, and in any case this is not the place to try to do so.

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