Health, Poverty, and Surgery in the US and Around the World

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HEALTH, POVERTY, AND SURGERY IN THE US AND AROUND THE WORLD

A dissertation presented

by

Mark George Shrime

to

The Harvard Committee on Higher Degrees in Health Policy

in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

in the subject of

Health Policy (Decision Sciences)

Harvard University

Cambridge, Massachusetts

April, 2015
Health, Poverty, and Surgery in the US and Around The World

ABSTRACT

Health improvement and financial ruin are often inexorably linked.

Nearly 30% of the global burden of disease is surgical [1], and over 30 million annual cases of financial ruin are attributable to accessing surgery [2]. In resource-poor countries, where 70% of all healthcare spending is out-of-pocket [3], catastrophic expenditure for medical care is extremely common [4-6]. In the United States, even those with health insurance face financial catastrophe: nearly two-thirds of bankruptcy is medical, and fully 75% of medically bankrupt individuals were insured at the time of their catastrophic medical bill [7]. Financial ruin is most pronounced among the global poor, among patients with life-threatening conditions, and, increasingly, among the elderly [2, 8-10].

As a result, although the World Health Organization [11], the United Nations [12], and the World Bank [13] have all called for financial risk protection in healthcare, medical impoverishment persists, sometimes forcing individuals into a choice between physical health and financial health.

Some choose the former and are willing to incur financial ruin to get care: they sell their assets, borrow, decrease consumption, or, catastrophically, face impoverishment in
the pursuit of health [4-6, 14-28]. Others respond to a risk of poverty by not complying with physician recommendations, by seeking alternate providers, or by forgoing care altogether [29-34]. In patients with serious conditions, these choices can be lethal [32, 35].

In the US, national health policy has consistently focused on decreasing out-of-pocket medical costs as a mechanism for health improvement—and not always successfully: two years after the initiation of the Oregon Medicaid expansion, for example, health outcomes had not changed dramatically [36]. Globally, policies to improve access to surgical care either mirror this demand-side focus on out-of-pocket cost reduction or address the supply-side dearth of surgical providers through policies such as task shifting [37-39].

The goal of this dissertation, then, is to examine the effects of these policies and platforms for global surgical delivery on health, on impoverishment, and on inequity, and to determine how individuals value tradeoffs among these outcomes.

Chapter 1 investigates the role of government policies for increasing surgical access in public hospitals. This extended cost-effectiveness analysis utilizes publicly available data from Ethiopia to evaluate the health, financial, and equity impacts of nine essential surgical procedures on rural patients. Five policies addressing supply- and demand-side barriers to surgical access are examined: 1) universal public financing (UPF), 2) task shifting (TS), 3) UPF with the addition of vouchers (V) to address the nonmedical costs of care, 4) UPF + TS, and 5) UPF + TS + V. I find that, while all policies are likely to improve
health, a tradeoff exists: TS averts deaths most dramatically, but does so at the cost of a large increase in financial catastrophe. UPF is more financially risk protective, but has a much smaller impact on health. Only policies that include vouchers for the non-medical costs of accessing care are found to provide an equitable distribution of benefits; the remaining policies continue to impoverish the poor.

Chapter 2 compares surgical delivery by charitable organizations with the governmental policies examined in Chapter 1. Using an agent-based model of cancer care in Uganda, the three common charitable platforms for surgical delivery—two-week “mission trips”, mobile surgical units, and free-standing specialty hospitals—are evaluated against combinations of UPF, TS, and V. In addition to health and catastrophic expenditure, two novel metrics are included to 1) incorporate the familial financial impact of a lack of access and 2) formalize the equitable distribution of benefits into a concentration index. I find that mobile surgical delivery platforms by non-governmental organizations can provide health and financial benefits equitably and efficiently and that they perform well when compared to health-system-strengthening policies. Other charitable platforms are equitable but are not efficient when compared with government policies. The results of this analysis also confirm the finding from Chapter 1 that equitable delivery platforms must address the non-medical costs associated with getting to care.

Chapter 3 tests the hypothesis that, in the setting of lethal disease, individuals value cure at all costs. A discrete choice experiment is undertaken in a nationally representative US sample of 2359 individuals. Respondents are asked to choose between two hypothetical treatments for a lethal disease, differing only in their chance of cure and
their risk of bankruptcy. I find that the resulting indifference curve is multiplicative, and that Americans are less willing to shoulder high risks of bankruptcy to increase their probability of cure than has been previously assumed. Subgroup and sensitivity analyses do not alter this relationship, although, in some groups, the difference in preference between bankruptcy protection and cure is not statistically significant. In no subgroup, however, do I find evidence a significant preference for cure at any cost in the American population.
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# Chapter One: Task Shifting or Public Finance to Increase Surgical Access in Rural Ethiopia: An Extended Cost-Effectiveness Analysis

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<tr>
<td>2W</td>
<td>Short-term (“two-week”) surgical trips</td>
</tr>
<tr>
<td>ABM</td>
<td>Agent-based model/agent-based modeling</td>
</tr>
<tr>
<td>CH</td>
<td>Free-standing cancer hospital</td>
</tr>
<tr>
<td>DALY</td>
<td>Disability-adjusted life-year</td>
</tr>
<tr>
<td>DCE</td>
<td>Discrete-choice experiment</td>
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<tr>
<td>ECEA</td>
<td>Extended cost-effectiveness analysis</td>
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<tr>
<td>FRP</td>
<td>Financial risk protection</td>
</tr>
<tr>
<td>LMIC</td>
<td>Low- and middle-income countries</td>
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<tr>
<td>MRS</td>
<td>Marginal rate of substitution</td>
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<td>MS</td>
<td>Mobile surgical unit</td>
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<td>OOP</td>
<td>Out-of-pocket</td>
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<tr>
<td>TS</td>
<td>Task shifting</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>UPF</td>
<td>Universal public financing</td>
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<td>V</td>
<td>Vouchers for the non-medical costs necessary to get to care (e.g., food, lodging, and transportation)</td>
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<td>WB</td>
<td>World Bank</td>
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ACKNOWLEDGMENTS

The convoluted road to this dissertation began over a decade ago, and countless companions have walked it with me. As much as I would like not to, some I will inadvertently forget. To them, I want to say thank you. Your absence on these pages is not due to your absence from my life.

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And at the end of this road, John Meara has—almost completely on faith—decided to take a gamble on a freshly-minted PhD intent on continuing that non-traditional career path. He has paved the way for those of us who want to make careers in academic global surgery, who want to wield scalpel and spreadsheet with equal facility. I look forward to working with him to advance this field.

On a more personal note: the four years of this PhD would have been drudgery were it not for the company of Teddy Svoronos, Hannah Neprash, Hummy Song, Liana
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My amazing ship family (I started listing you out by name, but gave up after I got to sixty people): when I first stepped into the wards of the *Africa Mercy*, I knew I had come home. I am in awe of you and the way you love the outcast, look the faceless in the eye and call them beautiful, dance with the crippled, sing with the voiceless, and restore to the exile the right to look human. You inspire me to do better, to love deeper, and to become smaller. You are an astounding community, bound by a higher call, and I am privileged to be a part of you.

Chief among this family are Gary and Susan Parker. Too many people proclaim their faith. Few have the sort of faith that informs every aspect of their lives. You are those few. To say that meeting you changed my life would be as cliché as it would be an understatement. Thank you for believing in me, for going to bat for me, and for letting me into your lives. Gary, if I came to Africa with a surgical foundation, you built the house. Thank you for countless conversations in your office, for teaching me to teach, for being the bravest surgeon I know. And Susan, thank you for your steadfastness, for pushing my theology, and for embodying grace. I only wish there were more hours in the day to sit over coffee and chocolate with you both and just talk.

In the end, though, not a single bit of this dissertation would have been possible without one person. Peggy, you picked me up when the PhD knocked me down. You believed in me before I believed in myself. You’ve been by my side through nearly thirty countries on six continents; through kidney stones in Kyrgyzstan and mountains of scree in New
Zealand; through rat offal stew in Liberia and dung-fired liver in Mongolia; through bell towers in Quito, tea in Darjeeling, and rambutans in Madagascar; through sprints up the Potala Palace, bushwhacking in Sierra Leone, and frigid swims in Lake Baikal. From Patagonia to the northern lights, animal markets to injuries, sea tortoises to moai, you’ve been there in the despair and you’ve been there in the exultation. We have led a life that is nothing short of adventure; I can’t wait to stand on mountains with you when we’re 70, leaning on walkers and canes, in high-waisted khakis, sundresses and floppy hats, wiping food off each other’s faces. You are my world.
Every thought I have imprisoned in expression,
I must free by my deeds

— Kahlil Gibran

Is this not the fast I have chosen:
to loose the bonds of wickedness and undo the straps of the yoke;
to set the oppressed free and to break every burden.
Is it not to share your bread with the hungry
and bring the homeless poor into your house?

— Isaiah the Prophet

The dog was dying and the man was sobbing, shedding tears, and crying, “Oh sorrow!” A beggar passed by and asked, “What is this sobbing? Whom do you mourn and lament?”
He replied: “I had a dog of excellent character. Look, he is dying on the road.”
The beggar asked, “What is wrong with him? Has he been wounded?” The man replied, “Ravenous hunger has made him so pitiful.”

Afterwards, the beggar said to him, “O noble chief, what is this full leather bag in your hand?”
He replied, “My bread and food left over from last night, which I am taking along with me to feed my body.”
“Why do you not give some bread and provision to the dog?” the beggar asked.
He replied, “I do not have that much love and generosity. Bread cannot be obtained without money. Water from the eyes is free.”

— Jalaluddin Rumi
In loving memory

Dr. George P. Shrimé

1940 – 1996
Chapter One:  
TASK SHIFTING OR PUBLIC FINANCE TO INCREASE SURGICAL ACCESS IN RURAL ETHIOPIA: AN EXTENDED COST-EFFECTIVENESS ANALYSIS
ABSTRACT

**Background:** Despite a high burden of surgical disease, access to surgical services in low- and middle-income countries is often limited. In line with the World Health Organization’s current focus on universal health coverage and equitable access to care, the objective of this chapter is to compare policies for expansion of access to surgery in rural Ethiopia.

**Methods:** An extended cost-effectiveness analysis was performed. Deterministic and stochastic models of surgery in rural Ethiopia were constructed, utilizing pooled estimates of costs and probabilities from national surveys and published literature. Model calibration and validation were performed against published estimates, with sensitivity analyses on model assumptions to check for robustness. Outcomes of interest were the number of deaths averted, the number of cases of poverty averted, and the number of cases of catastrophic expenditure averted for each policy, nominally and per dollar spent, divided across wealth quintiles.

**Results:** Health benefits from each of the examined policies accrued primarily to the poor. However, without vouchers paying for the non-medical costs of care, these policies also induced impoverishment in the poor while providing financial risk protection to the rich. Adding vouchers removed the impoverishing effects of a policy but decreased the health benefit per dollar spent. The distributional pattern of health and financial benefits was robust to sensitivity analyses.
**Conclusions:** Health benefits, financial risk protection, and equity may be in tension in the expansion of access to surgical care in rural Ethiopia. Policies to increase surgical access may improve health at the cost of increasing impoverishment, especially in the poor. Adding travel vouchers improves the financial risk protection of each policy but decreases how much health benefit can be bought per dollar.
1.1 INTRODUCTION
Up to 33% of the global burden of disease is surgical [1]. In low- and middle-income countries (LMICs), however, the utilization of surgical services is low, due often to a lack of surgical providers, facilities, and equipment; to sociocultural factors; and to the high cost of procedures [40-44]. A number of policies have been proposed to improve access to surgery, including making surgery free at the point of care and task shifting [37-39].

In Ethiopia, over 80% of the population of 92 million people lives in rural areas [45, 46], while most surgeons are located in cities. As a consequence, access to surgery is particularly low [47, 48]. For example 3.3% of women delivered their most recent child by Caesarean section in 2010—20% of women in Addis Ababa, but as few as 0.8% of the poorest women in rural Ethiopia [49]. While traditional preferences for home delivery play a role, rural women also point to the high cost of care and a lack of providers as reasons for low utilization [49, 50]. A surgical patient in Ethiopia faces, on average, $204 (1,125 Ethiopian Birr) in medical costs, as well as up to $611 in non-medical costs [51, 52].

The World Health Organization (WHO) posits that health systems have three objectives: to improve health, to provide financial protection, and to advance fair distribution of the two [53]. While health policies typically aim at the first objective, it is unclear whether improving health will necessarily accomplish the remaining two. In addition, standard health economic evaluations of policies tend to ignore their expected impact on the private economy of households.
In this chapter the health and financial risk protection benefits of policies for improving access to surgical care in rural Ethiopia are evaluated. Using an extended cost-effectiveness analysis (ECEA) framework [54-56], this chapter will compare

A) Universal public financing (UPF) that makes surgery free at the point of care, but does not pay for non-medical costs,

B) Task shifting (TS) of surgery to non-surgeon providers, and

C) A combination of UPF and TS.

In addition, because the non-medical costs necessary to access care—eg, for transportation, food, and lodging—can be significant drivers of both catastrophic expenditure and decisions to avoid care [57], two additional policies are examined:

D) UPF with the addition of vouchers, and

E) A combination of UPF, TS, and vouchers.

Finally, the distribution of these benefits across wealth groups will be quantified.

1.2 METHODS

1.2.1 SELECTION OF INTERVENTIONS

A basic package of surgery in rural Ethiopia is defined as the unit of analysis (Table 1·1). This package is chosen because the associated thirteen conditions have a large immediate risk of death [58-61] and, therefore, the interventions have a potentially large individual benefit. For this package, six scenarios are modeled: the five interventions described above and keeping surgical delivery at the status quo. Interventions that include UPF
work by transferring the medical cost of an intervention away from patients and onto the public sector. Task shifting models the impact of increasing the supply of surgical providers to the level found in urban Ethiopia. The addition of vouchers transfers the direct non-medical costs faced by patients onto the public sector.

**TABLE 1-1**: The nine surgical procedures and thirteen treated conditions included

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Treated conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendectomy</td>
<td>Acute appendicitis, complicated or uncomplicated</td>
</tr>
<tr>
<td>Exploratory laparotomy</td>
<td>Abdominal trauma</td>
</tr>
<tr>
<td>Caesarean section</td>
<td>Obstructed labor</td>
</tr>
<tr>
<td></td>
<td>Other fetal indications</td>
</tr>
<tr>
<td>Salpingectomy</td>
<td>Ectopic pregnancy</td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>Post-partum hemorrhage</td>
</tr>
<tr>
<td></td>
<td>Uterine rupture</td>
</tr>
<tr>
<td>Vacuum aspiration</td>
<td>Spontaneous abortion</td>
</tr>
<tr>
<td></td>
<td>Post-partum sepsis</td>
</tr>
<tr>
<td>Chest tube placement</td>
<td>Thoracic trauma</td>
</tr>
<tr>
<td>Amputation</td>
<td>Gangrene</td>
</tr>
<tr>
<td>Traction</td>
<td>Uncomplicated long-bone fracture</td>
</tr>
</tbody>
</table>

1.2.2. MODEL STRUCTURE, OUTCOMES, AND DATA SOURCES

1.2.2.1 MODEL STRUCTURE AND OUTCOMES OF INTEREST

Using ECEA methodology [54, 55], a synthetic population of 1,000,000 individuals similar in demographics to the population of rural Ethiopia is constructed and normalized to identically-sized wealth quintiles.

The structure of the model for one example surgical condition is given in Figure 1-1. Conditional on facing the modeled condition, a patient seeks care conditional on utilization barriers. If a patient chooses to access care, she experiences perioperative
morbidity or mortality, with probabilities as given in Table 1-2. Total costs, incremental costs, patient-borne costs, non-medical costs, and health benefits are calculated. This structure is essentially identical for all surgical conditions. The model assumes a single-event analytic horizon and, as such, assumes no discounting of costs and/or benefits.

**FIGURE 1-1**: Conditional-probability model for each surgical condition considered.

In this model, conditional on having one of the included conditions, the patient does or does not have access to surgical care. If she does, she has access from a surgeon or from a task shifted provider as documented in the text. Outcomes of surgical access, or a lack thereof, are modeled to the right.
The outcomes of interest were: deaths averted; cases of impoverishment averted; cases of catastrophic expenditure averted; average household cost savings (or “private expenditure crowded out”); and the incremental governmental costs, above the current status quo, needed to sustain the program.

**1.2.2.1.1 Deaths Averted**

For each intervention, the total deaths averted (TDA) are estimated based on incidence and mortality data, intervention effectiveness and case fatality rate.
TABLE 1-3: Estimated surgical utilization, given need, under each scenario

<table>
<thead>
<tr>
<th>Wealth</th>
<th>Status Quo</th>
<th>UPF</th>
<th>UPF + V</th>
<th>TS</th>
<th>UPF + TS</th>
<th>UPF+TS+V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poorest</td>
<td>0·033</td>
<td>0·057</td>
<td>0·11</td>
<td>0·21</td>
<td>0·24</td>
<td>0·29</td>
</tr>
<tr>
<td>Poor</td>
<td>0·065</td>
<td>0·080</td>
<td>0·11</td>
<td>0·31</td>
<td>0·32</td>
<td>0·35</td>
</tr>
<tr>
<td>Middle</td>
<td>0·096</td>
<td>0·11</td>
<td>0·13</td>
<td>0·40</td>
<td>0·41</td>
<td>0·44</td>
</tr>
<tr>
<td>Rich</td>
<td>0·13</td>
<td>0·14</td>
<td>0·16</td>
<td>0·50</td>
<td>0·51</td>
<td>0·52</td>
</tr>
<tr>
<td>Richest</td>
<td>0·19</td>
<td>0·19</td>
<td>0·20</td>
<td>0·69</td>
<td>0·69</td>
<td>0·69</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Obstetric conditions</th>
<th></th>
<th></th>
<th>Non-obstetric conditions</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Poorest</td>
<td>0·34</td>
<td>0·37</td>
<td>0·42</td>
<td>0·53</td>
<td>0·56</td>
<td>0·61</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0·42</td>
<td>0·44</td>
<td>0·47</td>
<td>0·59</td>
<td>0·61</td>
<td>0·64</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle</td>
<td>0·50</td>
<td>0·51</td>
<td>0·53</td>
<td>0·66</td>
<td>0·67</td>
<td>0·69</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rich</td>
<td>0·57</td>
<td>0·58</td>
<td>0·60</td>
<td>0·72</td>
<td>0·73</td>
<td>0·75</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Richest</td>
<td>0·64</td>
<td>0·65</td>
<td>0·65</td>
<td>0·79</td>
<td>0·79</td>
<td>0·79</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sources: [49, 95, 96]

For each surgical intervention treating condition \( j \) in wealth quintile \( k \), total deaths, \( TD_{j,k} \), can be determined using parameters listed in Table 1-2 and Table 1-3, and the chain of events exhibited in Figure 1·1. The deaths occurring in the status quo for condition \( k \), in a given quintile, \( j \), are estimated as follows:

\[
TD_{SQ,j,k} = [p_{a,j,k}d_{a,j,k} + (1 - p_{a,j,k})d_{n,j,k}] \times N_k \times p_j
\]  

(1·1)

where \( N_k \) represents the overall population in quintile \( k \), \( p_j \) represents the probability of an individual getting disease \( j \) (which is assumed not to vary across wealth quintiles), \( p_{a,j,k} \) represents the probability of accessing care by patients in wealth quintile \( k \) for disease condition \( j \), and \( d_{a,j,k} \) represents the probability of death given access to care.
Similarly, $d_{n,j,k}$ represents the probability of dying for patients in wealth quintile $k$ with disease $j$, conditional on not accessing care.*

Under task shifting, the probability of accessing care from a surgeon versus a task-shifted provider is estimated such that, in expectation, individuals who were accessing care from a surgeon under the status quo continue to access care from surgeons, and any induced demand as a result of the implementation of task shifting goes exclusively to task-shifted providers. In this case, $d_{a,j,k}$ varies by type of provider.

Total yearly deaths in the status quo can be determined by simply summing the deaths due to each condition in each wealth quintile, making the assumption that, over the course of one year, the chance that any individual gets more than one unrelated condition is minimal.

$$TD_{SQ} = \sum_k \sum_j TD_{j,k}$$  \hspace{1cm} (1.2)

Similar calculations are done for each policy intervention (UPF, task shifting, and combination). The total number of deaths averted by each policy is the difference

* To simplify the expression of this and following equations, all of the probabilities implied in Figure 1-1 are not explicitly represented in the equations. Instead, $d_{a,j,k}$ and $d_{n,j,k}$ represent the expected probability of dying, conditional on having reached the respective chance nodes. That is, $d_{n,j,k} = P(\text{Die of untreated disease}) \times 1 + P(\text{Survive/Resolve}) \times 0$. Similarly for $d_{a,j,k}$. 

between total deaths under the status quo and total deaths under the policy. For UPF, this becomes:

\[ TDA_{UPF} = TD_{SQ} - TD_{UPF} \]  \hspace{1cm} (1.3)

with identical calculations for the other policies.

1.2.2.1.2 CONSEQUENCES FOR HOUSEHOLD EXPENDITURES AND GOVERNMENT COSTS

Total system cost for each surgical intervention treating condition \( j \) in wealth quintile \( k \), \( SC_{j,k} \), can be determined following the conventions of Equation (1.1), with the addition of a cost-assignment factor, \( G \). In the status quo and under task shifting, \( G \) is 66%; in policies which make surgery free to the patient, \( G \) increases to 100%.

\[ SC_{j,k} = \left[ G \cdot p_{a,j,k}c_{a,j,k} + (1 - p_{a,j,k}) \cdot G \cdot c_{n,j,k} \right] \times N_k \times p_j \]  \hspace{1cm} (1.4)

where \( c_{a,j,k} \) represents the total cost of surgery when care is sought and \( c_{n,j,k} \) represents cost when care is not sought (assumed to be zero). System costs are estimated linearly for the first 10% increase in utilization, and then twice that for each additional increase, to approximate increasing marginal costs. Total and incremental costs are calculated identically to Equations (1.2) and (1.3).

Private expenditure due to surgical conditions is calculated similarly, with the inclusion, under the status quo, of the direct, non-medical costs of care, \( D_{j,k} \).
\[ PE_{j,k} = [p_{a,j,k}((1-G)c_{a,j,k} + D_{j,k}) + (1-p_{a,j,k}) \cdot (1-G) \cdot c_{n,j,k}] \times N_k \times p_j \] 

(1.5)

In this case, the out-of-pocket expenditure for medical care is the proportion not spent by the government, and, again, \( c_{n,j,k} \) is assumed to be zero. Expenditure averted is calculated identically to Equations (1.2) and (1.3).

### 1.2.2.1.3 Financial risk protection afforded

In addition to the crowdout of private expenditure, the financial risk protection (FRP) benefits brought to households by the program is measured as the number of cases of poverty and of catastrophic expenditure averted. Cases of catastrophic expenditure created under the status quo and each policy are calculated methods described previously [18, 25, 97]. Cases of poverty created under the status quo and each policy are calculated following the “head-count” method, also described previously [17, 98].

Briefly: each individual has a starting income, \( y_s \). Because reported income is not a valid indicator of overall wealth in LMICs [97], individual income, \( y \), is extracted from an income distribution for Ethiopia denoted \( f(y) \) [99].† Before the institution of any policy, each individual, \( s \), in wealth quintile, \( k \), with condition \( j \), has the following expected value of income:

†A proxy for an income distribution for Ethiopia, \( f(y) \), can be approximated using a Gamma distribution derived from Ethiopia’s gross domestic product (GDP) per capita (\$1366 in international dollars) and Ethiopia’s Gini index.
\[
E_{SQ,j,k}(y) = p_{a,j,k}(y_z - [(1 - G)c_{a,j,k} + D_{j,k}]) + (1 - p_{a,j,k})y_s
\] (1.6)

After the program, each individual has an expected value of income, \(E_{policy,s,j,k}(y)\), which is calculated as in Equation 1.6, with new cost and utilization parameters as above.

The threshold for expected income after catastrophic expenditure for each individual, \(T_s\), is calculated as a proportion of that individual’s starting income, \(y_s\). Following the methods outlined by multiple authors [18, 25, 97], \(T_s\) is set at 0.6, representing expenditure of 40% of the starting income. This represents the most conservative of the proposed thresholds [18]. The number of cases of catastrophic expenditure averted, \(TCA_{policy,k}\), by each policy in wealth quintile, \(k\), is

\[
TCA_{UPF,k} = \left[ \sum_s \sum_j I(E_{SQ,j,k}(y) < T_s y_s) \right] - \left[ \sum_s \sum_j I(E_{UPF,j,k}(y) < T_s y_s) \right]
\] (1.7)

where \(I(a < b)\) represents an indicator variable which takes the value 1 when the expression in brackets evaluates as true, and 0 otherwise. For the head count method, a national poverty line, \(PL\), is set and Equation (1.7) is repeated, with \(PL\) replacing \(T_s y_s\). In Ethiopia, 25% of the population lives below the national poverty line [49]; \(PL\) is therefore set at the 25th percentile of \(f(y)\). From Equation (1.7), it can be seen that a negative value for \(TPA_{policy,k}\) implies that the policy creates cases of catastrophic expenditure in quintile \(k\).
1.2.2.2 Model inputs and assumptions

Table 1-3 gives the estimated utilization for surgical services under each policy. Under the status quo, utilization for services for the poorest and richest quintiles was calculated from the 2011 Ethiopia DHS survey [49]. Utilization by intermediate quintiles represents a linear extrapolation between these two quintiles. Price elasticity in the demand for services in Uganda [100] was used as a proxy for responsiveness of patients to UPF and vouchers, with the demand increase proportional to the total cost of care (direct medical + direct non-medical) that was averted by each policy respectively. These own-price elasticities for care track well with older published estimates from Ethiopia [95, 96]. Utilization in Addis Ababa is taken to represent utilization when all necessary surgical providers are present.

As discussed above, the assumption is made that, under task shifting, no cross-over exists: the few patients who were already receiving care from a surgeon in the status quo continue to do so under task shifting. Under the combination of UPF and task shifting, in which surgery is made free and provider quantity is increased, patients utilize surgeons first, with the assumption being that, if the cost of medical care is free, the provider with the higher perceived quality will be chosen first; any excess demand is then borne by the task-shifted provider. Data for task shifting in non-obstetric surgical conditions were sparse. To calculate this gradient, utilization was anchored on the highest utilization in urban Ethiopia for medical services and on average utilization, and a linear gradient was
constructed to maintain that average and maximum utilization. Each of these assumptions is tested with sensitivity analyses.

Parameter estimates (Table 1·2 and Table 1·3) draw on national surveys and published studies. When possible, estimates were derived from rural Ethiopia, followed, in order, by estimates from urban Ethiopia, other east African countries, other sub-Saharan African countries, and other developing countries; finally, if no other data were available, estimates from the developed world were used.

All costs, including those from outside the Ethiopian context, are adjusted to and reported in international dollars, using purchasing power parity conversions and GDP deflator estimates published by the United Nations and the World Bank [52, 101]. Methodology for this conversion has been described previously [102].

Before the introduction of each program, individuals pay 34% of medical costs out of pocket (OOP), ranging from 19% to 78% [46, 64]. Direct non-medical costs to the patient (eg, transportation) are paid OOP under the UPF, task shifting, and UPF + task shifting scenarios, and shift to the public sector policies with vouchers.

To remain conservative, complication and mortality rates for non-surgeons were assumed to be 1·125 times those of surgeons [71]. Similarly, the costs of procedures performed by surgeons were assumed to be 1·47 times higher than those performed by non-surgeons.
[65, 66]. In the base-case analysis, the cost of complications was set at $25.50 [66], and varied in sensitivity analyses.

Direct costs included medical and non-medical costs. Medical costs included the inpatient costs of surgical delivery [51, 63-66]. Provider salaries are not explicitly added because this analysis is an incremental analysis and, as such, provider salaries would not change with the implementation of UPF or vouchers. Provider salaries in the setting of task shifting are addressed in a sensitivity analysis below.

Non-medical costs included the costs of transportation, food, and lodging and did not include the indirect costs of lost productivity. Due to increased travel costs to centralized providers, non-medical costs were assumed more expensive for care from surgeon than a non-surgeon ($611.66 and $297.45, respectively) [51]. Indirect costs (eg, lost productivity) were considered in sensitivity analyses.

Analyses were conducted using the R statistical software (www.r-project.org). Funders had no role in study design, data collection, writing, or submission for publication.

1.2.3 Sensitivity Analysis
In the base-case analysis, start-up costs for a task shifting program were not included. Sensitivity analysis was performed including these costs, based on published estimates from Mozambique [39] and unpublished estimates from Ethiopia. These included the
costs of salaries, training, library buildings, books, computers, and travel. These estimates were scaled linearly for differences in population size, and distributed evenly across the population. In addition, a sensitivity analysis was performed in which the complication rates of trained surgeons and of task-shifted providers were equivalent.

Additional sensitivity analyses included changes in baseline utilization, price elasticity of demand, the magnitude of non-medical costs, mortality from untreated disease, the cost of complications, the inclusion of indirect costs, and the effects of taxation. Finally, heterogeneity in estimates was modeled using first-order Monte-Carlo simulation.

1.3 RESULTS
1.3.1 Model Contextualization and Validation
From the 2011 Ethiopia DHS survey [49], the overall rate of delivery in a medical facility was calculated to be 16.5%, which is identical to published estimates [50].

The model was then validated against published mortality estimates from the World Bank, the United Nations Population Fund (UNFPA), UNICEF, and the World Health Organization. The model estimated 9112 maternal deaths per year in Ethiopia, consistent with estimates of 9000 [103]; this translates to a predicted maternal mortality ratio of 368 deaths per 100,000 live births, which is also consistent with World Bank estimates of 350 [104]. The model predicted 0.62 deaths per 1000 from traumatic conditions and 0.012
deaths per 1000 from appendicitis, consistent with World Bank estimates (0.61 and 0.012, respectively) [105].

1.3.2 Base case analysis, without travel vouchers

1.3.2.1 Health impacts
Health benefits, measured in deaths averted, nominally and per $100,000 spent, are shown in Table 1.4 and Table 1.5. Per million people per year in rural Ethiopia, UPF averted 21 deaths, at a cost of $895,000 (3.0 averted deaths per $100,000 spent, or $33,300/death averted). Task shifting was predicted to avert 250 deaths per million per year in rural Ethiopia, at a cost of $377,200 (65 averted deaths per $100,000, or $1500/death averted). Finally, combining both task shifting and UPF was predicted to cost the system $2,230,000 per million people per year, and to avert 291 deaths, for a total of 14 deaths averted per $100,000 spent ($2222/death).

Health benefits were not distributed evenly across wealth quintiles. The primary beneficiaries of UPF were the poorest. Under task shifting, overall benefits were similar across wealth quintiles, but the richest benefited most from obstetric interventions, and the poorest from interventions in trauma and appendicitis. The combination of the two policies maintained a gradient similar to that seen in UPF, but with additional health benefits accruing to the richest quintile.
### TABLE 1.4: Benefits per million in the population, per $100,000 spent

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Wealth Quintile</th>
<th>Poorest</th>
<th>Poor</th>
<th>Middle</th>
<th>Rich</th>
<th>Richest</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths averted per $100,000 spent</td>
<td>UPF</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>UPF + V</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>TS</td>
<td>62</td>
<td>64</td>
<td>66</td>
<td>68</td>
<td>72</td>
<td>65</td>
</tr>
<tr>
<td></td>
<td>UPF + TS</td>
<td>17</td>
<td>15</td>
<td>13</td>
<td>12</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>UPF + TS + V</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Poverty averted per $100,000 spent</td>
<td>UPF</td>
<td>0</td>
<td>-24</td>
<td>-21</td>
<td>221</td>
<td>0</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>UPF + V</td>
<td>0</td>
<td>88</td>
<td>124</td>
<td>38</td>
<td>0</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>TS</td>
<td>0</td>
<td>-458</td>
<td>-288</td>
<td>0</td>
<td>0</td>
<td>-155</td>
</tr>
<tr>
<td></td>
<td>UPF + TS</td>
<td>0</td>
<td>-101</td>
<td>-59</td>
<td>91</td>
<td>0</td>
<td>-11</td>
</tr>
<tr>
<td></td>
<td>UPF + TS + V</td>
<td>0</td>
<td>50</td>
<td>70</td>
<td>22</td>
<td>0</td>
<td>30</td>
</tr>
<tr>
<td>System cost</td>
<td>UPF</td>
<td>$143,557</td>
<td>$157,208</td>
<td>$177,427</td>
<td>$199,106</td>
<td>$217,388</td>
<td>$894,686</td>
</tr>
<tr>
<td></td>
<td>UPF + V</td>
<td>$900,044</td>
<td>$965,874</td>
<td>$1,080,332</td>
<td>$1,205,597</td>
<td>$1,305,738</td>
<td>$5,457,585</td>
</tr>
<tr>
<td></td>
<td>TS</td>
<td>$82,233</td>
<td>$78,768</td>
<td>$75,303</td>
<td>$71,838</td>
<td>$69,053</td>
<td>$377,195</td>
</tr>
<tr>
<td></td>
<td>UPF + TS</td>
<td>$377,166</td>
<td>$406,668</td>
<td>$443,739</td>
<td>$482,492</td>
<td>$518,549</td>
<td>$2,228,614</td>
</tr>
<tr>
<td></td>
<td>UPF + TS + V</td>
<td>$1,571,597</td>
<td>$1,713,118</td>
<td>$1,903,268</td>
<td>$2,104,225</td>
<td>$2,283,758</td>
<td>$9,575,967</td>
</tr>
</tbody>
</table>

Health gains, financial risk protection (measured in cases of poverty averted), and costs for UPF (with and without vouchers), task shifting, and task shifting combined with UPF (with and without vouchers) for the modeled surgical interventions in rural Ethiopia. Health and financial risk protection benefits are measured per $100,000 spent. Note that negative numbers of cases of poverty averted represent cases of impoverishment created by the policy. Numbers are rounded to the nearest whole. UPF = universal public finance. TS = task shifting. V = vouchers

### TABLE 1.5: Nominal benefits, per million in the population

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Wealth Quintile</th>
<th>Poorest</th>
<th>Poor</th>
<th>Middle</th>
<th>Rich</th>
<th>Richest</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths averted per $100,000 spent</td>
<td>UPF</td>
<td>8</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>UPF + V</td>
<td>23</td>
<td>14</td>
<td>10</td>
<td>8</td>
<td>2</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>TS</td>
<td>51</td>
<td>50</td>
<td>50</td>
<td>49</td>
<td>50</td>
<td>250</td>
</tr>
<tr>
<td></td>
<td>UPF + TS</td>
<td>63</td>
<td>59</td>
<td>57</td>
<td>56</td>
<td>55</td>
<td>291</td>
</tr>
<tr>
<td></td>
<td>UPF + TS + V</td>
<td>76</td>
<td>67</td>
<td>63</td>
<td>60</td>
<td>56</td>
<td>324</td>
</tr>
<tr>
<td>Poverty averted per $100,000 spent</td>
<td>UPF</td>
<td>0</td>
<td>-38</td>
<td>-37</td>
<td>440</td>
<td>0</td>
<td>366</td>
</tr>
<tr>
<td></td>
<td>UPF + V</td>
<td>0</td>
<td>850</td>
<td>1339</td>
<td>461</td>
<td>0</td>
<td>2650</td>
</tr>
<tr>
<td></td>
<td>TS</td>
<td>0</td>
<td>-361</td>
<td>-217</td>
<td>0</td>
<td>0</td>
<td>-578</td>
</tr>
<tr>
<td></td>
<td>UPF + TS</td>
<td>0</td>
<td>-409</td>
<td>-260</td>
<td>440</td>
<td>0</td>
<td>-229</td>
</tr>
<tr>
<td></td>
<td>UPF + TS + V</td>
<td>0</td>
<td>850</td>
<td>1339</td>
<td>461</td>
<td>0</td>
<td>2650</td>
</tr>
</tbody>
</table>

Nominal (ie, not per-dollar-spent) health gains and financial risk protection afforded (measured in cases of poverty averted), spent on UPF, task shifting, and task shifting combined with UPF for surgical interventions in rural Ethiopia. Numbers have been rounded to the nearest whole and therefore may not sum. UPF = universal public finance. TS = task shifting. V = vouchers
1.3.2.2 Poverty Impacts
Without vouchers, only UPF had financially risk protective effects. Task shifting induced impoverishment on average, and the addition of UPF only incompletely mitigated this impoverishment (Table 1.4 and Table 1.5). UPF averted 366 cases of poverty per million in the population, amounting to approximately 44 cases for every $100,000 spent. Poverty was, however, created in the poorest wealth quintiles (see discussion for an explanation of the poorest wealth quintile). The rich and richest patients alone saw a financial benefit from UPF.

Task shifting created 578 cases of poverty per million in the population, or approximately 155 cases created for every $100,000 spent. No impoverishment was averted, and most impoverishment accrued to the poorest three quintiles. Finally, a policy that combined task shifting with UPF created 229 cases of poverty, or 11 cases per $100,000 spent. The distribution of financial risk protection was similar to that seen in UPF.

1.3.3 Health and Financial Benefits with Vouchers
When non-medical costs of care-seeking were transferred away from patients, overall health benefits increased because of increased demand. However, because these interventions are more expensive, fewer health benefits could be bought per dollar. In contrast, these vouchers bought significantly more financial risk protection.
UPF + vouchers averted only 1 death per $100,000 spent, but averted 52 cases of poverty ($1900/case of poverty averted). Combining UPF, task shifting, and vouchers averted 4 deaths and 30 cases of poverty per $100,000 ($25,000/death and $3333/case of poverty).

Distributionally, financial risk protection continued to accrue primarily to the richer quintiles, while health benefits accrued to the poorest. A comparison of the health benefits and the financial risk protection benefits for each policy is provided in Figure 1.2, and the distributional impacts are shown in Figure 1.3.

**FIGURE 1.2**: Health protection versus financial risk protection per $100,000 spent.

Note that, in the absence of vouchers, policies create cases of poverty, driven, in large part, by direct non-medical costs, which are averted by the introduction of vouchers. UPF = universal public finance.
1.3.3.1 Private expenditure crowded out
On average, UPF led to crowdout of $0.85 of private expenditure per person on surgical conditions, ranging from $1.09 in the richest quintile to $0.72 in the richest quintile. Task shifting led to crowdout of $0.38 per person, highest in the poorest quintile ($0.41) and lowest in the richest quintile ($0.35). A combination of the two policies crowded out $2.14 per person, highest in the richest quintile ($2.59) and lowest in the poorest quintile ($1.89).

Adding vouchers to UPF led to crowdout of $5.19 per person ($4.50, poorest; $6.53, richest), while adding them to UPF + task shifting had the highest impact on average household savings ($9.11 average; $7.86 poorest; $11.42 richest).

1.3.3.2 Cases of catastrophic expenditure averted
Per $100,000 spent, UPF induced 355 extra cases of catastrophic expenditure; task shifting created 40 cases and the combination of the two created 120 cases. In all three policies, catastrophic expenditure fell primarily on the poorest wealth quintiles. The richest quintile saw protection against forced borrowing and selling from UPF and the combination policy (Figure 1.4).

Adding vouchers averted catastrophic expenditure across all wealth quintiles, with nearly 4000 cases averted per $100,000 spent for UPF + vouchers, and 512 cases averted for UPF + task shifting + vouchers.
FIGURE 1.3: Distribution of health and poverty protection across wealth quintiles, per \$100,000 spent.

UPF = Universal public finance. TS = Task shifting. V = vouchers
1.3.4 Sensitivity Analysis

1.3.4.1 Adding the Costs of Scaleup, Changing Complication Rates, and Adding Heterogeneity

Adding the costs for scale-up of task shifting decreased the health benefit per dollar on any policy that included task shifting by a small amount; it had a similarly marginal effect on the distributional equity of health and financial risk protection outcomes (not shown). Equalizing the complication rates between surgeons and task-shifted providers did not significantly change the outcomes. The addition of heterogeneity to the model is shown in Figure 1.5.
FIGURE 1.4: Distribution of health and catastrophic expenditure protection across wealth quintiles, per $100,000 spent..

UPF = Universal public finance. TS = Task shifting. V = vouchers.
FIGURE 1·5: Heterogeneity in results for each of the five policies.  
UPF = Universal public finance.

1·3·4·2 Changing baseline utilization
Under base-case assumptions, the status quo utilization for non-obstetric services is proxied by utilization of the health system in general. This is likely an upper bound. For this sensitivity analysis, a more conservative assumption was made: the proportion of all respondents in the DHS survey who accessed care from a hospital specifically was used, pooled with data from a 1994-1997 household survey [106]. Price elasticities were applied as described above, leading to utilization numbers shown in Table 1·6.
Results are given in Figure 1-6. Most policies have higher benefits and harms per dollar spent. This effect is most pronounced with UPF. Both task shifting and UPF + task shifting still induce impoverishment on average.

1.3.4.3 Own-price elasticity of demand
In the base case, the assumptions on increased demand under UPF are relatively inelastic, consistent with estimates for own-price elasticity for public services in Uganda. This sensitivity analysis assumes an increased own-price elasticity for health services, consistent with that found for private health provision [100]. The resultant utilization functions are given in Table 1-7.
FIGURE 1-6: Health and financial risk protection per $100,000 spent under assumptions of decreased status quo utilization for non-obstetric conditions.

### TABLE 1-7: Estimated surgical utilization, given increased own-price elasticity

<table>
<thead>
<tr>
<th>Wealth</th>
<th>Status Quo</th>
<th>UPF</th>
<th>UPF + V</th>
<th>TS</th>
<th>UPF + TS</th>
<th>UPF+TS+V</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Obstetric conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest</td>
<td>0.033</td>
<td>0.13</td>
<td>0.35</td>
<td>0.21</td>
<td>0.33</td>
<td>0.53</td>
</tr>
<tr>
<td>Poor</td>
<td>0.065</td>
<td>0.11</td>
<td>0.20</td>
<td>0.31</td>
<td>0.36</td>
<td>0.44</td>
</tr>
<tr>
<td>Middle</td>
<td>0.096</td>
<td>0.12</td>
<td>0.18</td>
<td>0.40</td>
<td>0.43</td>
<td>0.48</td>
</tr>
<tr>
<td>Rich</td>
<td>0.13</td>
<td>0.14</td>
<td>0.17</td>
<td>0.50</td>
<td>0.51</td>
<td>0.53</td>
</tr>
<tr>
<td>Richest</td>
<td>0.19</td>
<td>0.19</td>
<td>0.19</td>
<td>0.69</td>
<td>0.68</td>
<td>0.68</td>
</tr>
<tr>
<td><strong>Non-obstetric conditions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest</td>
<td>0.34</td>
<td>0.46</td>
<td>0.66</td>
<td>0.53</td>
<td>0.67</td>
<td>0.84</td>
</tr>
<tr>
<td>Poor</td>
<td>0.42</td>
<td>0.47</td>
<td>0.56</td>
<td>0.59</td>
<td>0.65</td>
<td>0.73</td>
</tr>
<tr>
<td>Middle</td>
<td>0.49</td>
<td>0.52</td>
<td>0.57</td>
<td>0.66</td>
<td>0.69</td>
<td>0.74</td>
</tr>
<tr>
<td>Rich</td>
<td>0.57</td>
<td>0.58</td>
<td>0.61</td>
<td>0.72</td>
<td>0.74</td>
<td>0.76</td>
</tr>
<tr>
<td>Richest</td>
<td>0.64</td>
<td>0.64</td>
<td>0.64</td>
<td>0.79</td>
<td>0.78</td>
<td>0.78</td>
</tr>
</tbody>
</table>
Results are given Figure 1-7. Minor changes are noted in the amount of health benefit and financial risk protection benefit when compared with the base case scenario. UPF results in less financial risk protection per dollar than in the base-case scenario because the increased price elasticity exposes more patients to the direct non-medical costs; it does, however, result in a marginal increase in health protection per dollar. The same pattern is seen in task shifting and task shifting + UPF. The programs with vouchers show an increase in both health and financial risk protection benefits, as expected.

No differences were noted in the distribution of benefits across wealth quintiles for any of the proposed policies.

1.3.4.4 Magnitude of direct non-medical costs
In the base-case analysis, the non-medical cost for services ran approximately three times the cost of actual medical services. In this sensitivity analysis, that cost differential is equalized. Utilization is recalculated using the resultant new total cost of care. As shown in Figure 1-8, all policies now avert more cases of impoverishment, and only task shifting creates impoverishment overall. However, although UPF + task shifting now has an overall financial risk protective effect, it continues to create impoverishment in the poorest two quintiles (not shown).
FIGURE 1.7: Health and financial risk protection per $100,000 spent under assumptions of increased own-price elasticity.
1.3.4.5 Risk of Mortality from Untreated Disease
Under the base case, the assumed risk of mortality from untreated disease in six of the examined conditions (obstructed labor, maternal sepsis, uterine rupture, other conditions requiring C-section, other conditions requiring hysterectomy, and conditions requiring abortion) is 30%. Although this assumption is supported by the literature (see above), it will necessarily bias the results away from the implementation of any policy when health benefits are of interest. As a result, this sensitivity analysis explores the impact of these policies, conditional on an untreated mortality of 90% for any of these six conditions. Results are shown in Figure 1.9. Per dollar spent, UPF and UPF + vouchers are essentially
unchanged from the base-case results. Policies involving task shifting, however, avert more deaths per dollar spent, with the largest difference seen in the policy of task shifting alone. The additional health benefit per dollar gained under task shifting in this sensitivity analysis is diluted when additional policies (UPF and vouchers) are included. There is no change in the overall distribution of benefits across wealth quintiles (not shown).

**FIGURE 1-9:** Health and financial risk protection per $100,000 spent under assumptions of increased mortality from untreated disease.
1.3.4.6 Increasing the cost of complications.

The cost of complications is low relative to the cost of any individual procedure. This sensitivity analysis therefore varies the cost of complications up to a maximum of three times the cost of the procedure. The results at this upper bound are shown in Figure 1.10. As expected, all policies avert fewer deaths per dollar than under base case assumptions; this effect is most obvious for task shifting alone, in which the probability of complications is highest. As well, because these policies become more expensive, financial impacts per dollar decrease. The distribution of benefits across wealth quintiles remains unchanged (not shown).

**FIGURE 1.10**: Health and financial risk protection per $100,000 spent under assumptions of increased costs for complications.
1.3.4.7 Including indirect costs
There are two possible sources of indirect cost in this model: the first is the indirect cost involved in care seeking (due, for example, to lost wages for patients and caretakers). This indirect cost has been estimated elsewhere, at $371.74 for care sought through the referral system and $243.52 when care is sought through an outreach program [51].

Taking the arguably conservative assumption that these indirect costs factor into the patient’s decision to seek care (which, given the life-threatening nature of the conditions examined, is unlikely), the model was re-run, with results shown in Figure 1.11. More impoverishment is created and less impoverishment averted for each policy under this assumption than under the base case assumptions. These differences are, again, seen most strongly in task shifting but occur under all policies. The decreased financial risk protection accrues across all wealth quintiles, and is most marked under task shifting—the rich now see impoverishment when indirect costs are included, which is not seen in the base case.

When the more realistic assumption that patients’ demand for care is sensitive only to their direct out-of-pocket costs is taken, the inclusion of these indirect costs leads to the creation of more impoverishment across the entire population (Figure 1.12) when compared to the base case and the sensitivity analysis in Figure 1.11. The salutary effects of UPF ameliorated some of that increased impoverishment when added to task shifting, but not all of it. The distributional impacts were similar to those seen in the sensitivity analysis in Figure 1.11.
Including the second source of indirect costs—the loss of economic productivity due to the death of a patient—is more problematic. From a societal perspective, this loss is significant. However, given the perspective of this model, accounting for this cost runs the risk of double-counting deaths and impoverishment. As a result, a third sensitivity analysis was done, to approximate a benefit-cost analysis. As a back-of-the-envelope calculation, the value of a death was set as follows: most patients facing these conditions are assumed to be 25 years of age and would, therefore, have a life expectancy of an additional 38.4 years. Given the average income of an adult in Ethiopia (ETB 593.3) [51], a death was calculated to have a cost to society of $49,798.30. Per million in the population, keeping surgical delivery at the status quo costs $50,563 million. Taking a benefit-cost perspective, task shifting plus UPF, at $38,28 million, is the preferred option, followed by task shifting alone (I$38.48M), task shifting + UPF + vouchers ($44.02M), and UPF alone ($50.41M). UPF plus vouchers is more expensive than keeping delivery at the status quo and is therefore dominated.
FIGURE 1-11: Health and financial risk protection per $100,000 spent when indirect costs are included and patients consider these costs in their decisions to seek care.

FIGURE 1-12: Health and financial risk protection per $100,000 spent when indirect costs are included and patients do not consider these costs in their decisions to seek care.
1.3.4.8 The effects of taxation
Although the model does not specifically adopt a societal standpoint, the costs of any intervention are assumed to be exogenous. This sensitivity analysis examines the effect of making these costs endogenous through taxation. For this sensitivity analysis, a flat tax is applied to the entire population. Flat taxation is necessarily simplistic; the effects of progressive and regressive taxation schemes are not explicitly modeled. Results are shown in Figure 1.13. Applying a flat tax to pay for full implementation of the policies of interest leads to impoverishment across all policies. This impoverishment load is borne by the poorest two quintiles (in policies with vouchers) and the poorest three quintiles (in policies without vouchers). Financial risk protection continues to accrue to the rich in all policies and to the middle quintile in policies with vouchers, but this risk protection effect is blunted when compared with the base-case scenario.
**FIGURE 1.13:** The effect of paying for each policy using a flat tax across the population. Note that the impact represented here is for the entire population. Cases of medical impoverishment do not fall equally across wealth quintiles.

### 1.4 DISCUSSION

Using an ECEA framework [54-56], this chapter examines the health and financial risk-protection benefits of five policies to increase surgical access in rural Ethiopia: making surgery free at the point of care (UPF); task shifting; a combination of UPF and task shifting; UPF with the addition of vouchers; and, finally, a combination of UPF, task shifting, and vouchers.

While surgical services in Addis Ababa approximate those offered in many higher-income countries [107], care in rural Ethiopia is sparse [108]. Because of a lack of providers and a high cost [47, 48], many surgical conditions go untreated, enlarging the burden of
surgical disease in this country. Evaluations of policies to improve access to surgery in
this setting are therefore needed.

The provision of universal health care is a focus of the World Health Organization [109];
as such, UPF has been proposed for interventions ranging from rotavirus vaccination [54],
to dental services [38], to emergency obstetric care [37]. Task shifting has also been
promoted, with non-specialist doctors and non-physicians increasingly filling a deficit in
medical services [110] and emergency obstetric care [39, 111, 112]. This chapter examines
these policies in the setting of surgery.

Unlike many global health interventions, however, surgery is a relatively nebulous
service, whose borders are indistinct. As a result, it is often provided by disparate, poorly-
organized platforms [113]. To facilitate analysis, a bundle of surgical procedures for
thirteen conditions was defined and a model built based on data from nationwide surveys
and the published literature [49]. This model proved well-calibrated to current health
outcomes in Ethiopia [50].

The results of this analysis explicitly illustrate tradeoffs between health protection and
financial risk protection. Although UPF provides both, it serves primarily as a financial
risk protection policy. Task shifting buys a lot of health per dollar spent, at the cost of a
counterintuitive increase in impoverishment. Adding UPF to task shifting mitigates this
impoverishment, but only partially. Although the poor gain the most health benefit in all
policies except for task shifting, impoverishment also falls most heavily on them. Note that a head-count impoverishment metric counts of the number of individuals pushed below the national poverty line. One-quarter of Ethiopians live below the poverty line—so, by definition, the poorest wealth quintile cannot be impoverished by any expenditure. A catastrophic expenditure metric, as in Figure 1.4, unmasksthe worsening of impoverishment in the poorest quintile, which is masked by the head-count metric.

The counterintuitive increase in impoverishment in some quintiles is due to the fact that, while demand for surgical services is induced by some policies, these services are not always free, and patients still have to pay for the non-medical costs of obtaining care. For many patients, these prove catastrophic [57]. This is made explicit when vouchers are included in the model. Poverty is no longer created, but, because these policies are significantly more expensive, the amount of health benefit achieved per dollar spent drops drastically.

Although cost/QALY cannot be calculated using the methodology employed here, a rough approximation (using the median age in Ethiopia of 16.8 and average life expectancy, conditional on attaining that age, of 52.1 additional years) [46] predicts that a life year gained will cost between $7200 (task shifting) and $184,000 (task shifting + UPF + vouchers).
There are limitations to this analysis. Measuring impoverishment is difficult and some authors suggest that, instead of the head-count method or catastrophic expenditure, a movable threshold [114], or measures of depth of poverty [17], are more appropriate. All methods are limited in that they do not measure the financial burden of a lack of access. That is, were a bread-winner to suffer a catastrophic health event, her death may throw an entire household into poverty. This is not explicitly addressed in this current analysis, and is left to Chapter 2.

The strength of this analysis is in what it can show: it highlights the significant tradeoffs inherent in policies for increasing access to surgical care in LMICs, tradeoffs that are not dissimilar from those seen in developed countries [36]. In addition, it highlights the distribution of these benefits: UPF appears primarily to improve financial risk protection among the richer segments of the rural Ethiopian population; the small benefits it has on health, on the other hand, accrue to the poorest. Conversely, task shifting creates cases of poverty while averting deaths across the entire population; the latter benefit primarily accrues to the richest, while the former harm accrues to the poorest.

Because these are counterintuitive findings, the model was tested with multiple sensitivity analyses. These included: equalizing the complication rates between task shifted providers and surgeons; allowing the demand function to be more price-elastic, including the costs of start-up for a task shifting program, increasing the probability of dying from untreated disease, decreasing baseline utilization estimates, decreasing the
non-medical cost, increasing the cost of complications, including indirect costs, and modeling the effect of taxation. Although the magnitude of the benefits bought per dollar changes with these sensitivity analyses, the changes are small. More importantly, except in the case of taxation, the distribution of the benefits across wealth quintiles is robust to these sensitivity analyses.

How one decides among the modeled policies remains a matter of further research, patient-preference analyses, political debates and ethical analyses. Making normative statements about these policies and their potential unintended consequences on income inequality is not the goal of this chapter. Instead, this analysis is presented to facilitate open, fair, and well-informed deliberative processes for making these decisions.

1.5 CONCLUSION
This chapter examines, simultaneously, the health and financial benefits of policies for improving surgical access in a developing-world context. It highlights tensions between the two and makes explicit their distributional patterns across wealth quintiles. Task shifting appears simultaneously to improve the health of rural Ethiopia but to put the poor at significant risk of impoverishment. On the other hand, making surgery free protects against impoverishment in the rich; health benefits and impoverishment both accrue to the poor. Further research is warranted to refine how to choose among these disparate policy benefits.
Chapter Two:
Surgical Oncology by Non-Governmental Organizations in Uganda: An Agent-Based Model
ABSTRACT

Background: Cancer can be both lethal and impoverishing in low- and middle-income countries. Simultaneously the high costs of care and a lack of providers contribute to poor health utilization. Policies and platforms to address these barriers to care have been proposed by governments and non-governmental organizations (NGOs). How these proposals impact health, impoverishment, and equity is not known.

Methods: An agent-based extended cost-effectiveness analysis was performed in Uganda with three aims: to compare NGO platforms with public sector interventions; to propose and evaluate novel metrics for measuring the financial burden of a lack of healthcare access and the equitable distribution of benefits; and to demonstrate the benefit of agent-based modeling in answering health policy questions. The numbers of lives saved, catastrophic expenditure averted, impoverishment averted, costs, and equity of nine proposals were compared. Sensitivity and scenario analyses were performed to test robustness to model assumptions.

Results: Mobile NGO surgical units can prevent cancer deaths and impoverishment efficiently and equitably. They compare favorably with governmental policies that address supply and demand barriers, including the costs of getting to care. Policies that only remove user fees alone are explicitly dominated, as is the commonly employed short-term NGO “surgical mission trip”. Agent-based modeling provides benefits not seen in
other techniques, including the ability to leverage geographic constraints and to count the financial burden of a lack of access.

**Conclusions:** Mobile surgical units and policies that strengthen the entire health system and remove the costs of getting to care are able to improve cancer care in Uganda in a manner that addresses health and financial risk protection equitably. Other policies and platforms are either inefficient or do not demonstrate equitable distribution of benefits.
2.1 INTRODUCTION
The expense and complexity of cancer care prevent some patients in low- and middle-income countries (LMICs) from getting treatment and risk impoverishing those who do. This double-edged effect falls most heavily on the poor. Multiple governmental policies and non-governmental delivery platforms have been proposed to improve access to care. While increased access can reasonably be expected to lead to health benefits, financial and equity impacts have not been studied in detail. This chapter aims to determine how cancer surgery delivered by non-governmental organizations (NGOs) in Uganda compares with public sector interventions along the domains of health, impoverishment, and equity. In doing so, novel metrics are proposed and methodology not often applied to health services research is utilized. The intention is that policymakers can use these results in designing rational health systems around oncology care.

2.1.1 SURGERY AND THE ONCOLOGIC BURDEN
The burden of oncologic disease is heavy in LMICs: both deaths and disability-adjusted life years (DALYs) attributable to cancer have increased more rapidly in LMICs than elsewhere [115], and, in some LMICs, the ratio of cancer diagnoses to cancer deaths is nearly 1:1, highlighting a marked lack of access to screening and treatment options [116, 117].

Although ideal cancer treatment is multidisciplinary, surgery is involved in 60-90% of oncologic disease [1]. In LMICs the absence of multimodality treatment often consigns
oncology patients to a complete lack of treatment, even when some potentially curative modalities—such as surgery—are available [118]. Historically, hospitals in LMICs have avoided treating cancer, focusing instead on lower-DALY and lower-cost surgical conditions—such as urologic diseases and hernias—and those patients with higher-cost/higher-DALY conditions treated at these hospitals are frequently lost to follow-up [42].

Simultaneously, a large and rapidly growing charitable sector has set itself up as a parallel, but fragmented, delivery system [119, 120]. These surgical charities operate under three basic delivery models: short-term surgical trips, self-contained mobile surgical units, and free-standing specialized surgical hospitals [113]. Despite a stated preference by patients for government health services over services delivered by NGOs [121], up to 20% of care and 55% of surgery is provided by the NGO sector [122-124].

2.1.2 HEALTH AND IMPOVERISHMENT
Cancer patients face an obvious risk to their lives. Worldwide, they also face impoverishment. In the US, half of patients receiving bone-marrow transplantation report significant financial burden [125], and nearly two-thirds of bankruptcy nationwide is medical [126], a risk which is significantly higher in the poor and in cancer patients [8, 9]. In LMICs [4-6], catastrophic spending and forced borrowing and selling are common mechanisms to fund medical care [6]. For cancer patients, financial burden itself drives
poorer health outcomes: in Nigeria, one-fifth of children presenting with a rapidly lethal tumor did not get treated because of cost [32].

In 2007, the World Health Organization (WHO) posited that health systems should, in addition to improving health, provide financial risk protection from the high costs of care [11]. The WHO is not alone: the World Bank has also set a global goal to eliminate medical impoverishment by 2030 [127]. Unfortunately, improving health and alleviating impoverishment are not always aligned, as seen in Chapter 1. Policies to improve the supply of healthcare may actually increase the risk of financial catastrophe [128],† while other policies that improve financial risk protection have only minimal impacts on health [36].

Evaluating the financial impacts of care is complicated by difficulty in measurement. Many metrics have been proposed, including

- Any expenditure (yes/no) [97]
- Amount of expenditure [97]
- Catastrophic expenditure [6, 129, 130]
- Poverty head count [131]
- Poverty gap or squared poverty gap [131]
- Indebtedness [97]

† This statement is counterintuitive. It hinges on the fact that an increase in medical providers induces demand that may have been previously latent or nonexistent. The providers are not, however, free, and some patients may spend catastrophically to access them.
• Borrowing and selling to pay for care [4].

Borrowed from the taxation literature [131], these metrics share an inherent limitation: they all require the individual to spend something to be counted. This requirement is problematic in healthcare, because it cannot measure the financial burden of a lack of access. The increase in impoverishment from supply-side interventions, for example, is potentially driven by the fact that individuals who might have died from their disease previously now have access to surgeons, but at a cost they were not previously facing [128]. This alleviates the financial burden of a lack of access but increases the financial burden inherent in getting care, a tension not measured by any metric above.

In addition, most measures of financial burden in health have, to date, measured only the direct medical costs of care. This does not reflect the full cost to patients, as the non-medical costs of getting to care can be significant, can prevent access, and can themselves impoverish those who get treatment [128, 132]. Measuring the full health and financial burdens of cancer therapy must address these issues.

2.1.3 The Ugandan context
Uganda is an East African country of 37.5 million people [133]. Fully 85% of its population is rural [133]. With a human development index of 0.484, Uganda ranks 164th out of the 187 countries ranked [134]. The country has 8 physicians per 100,000 in the population [133], of whom only 7.5% are surgeons or anaesthesiologists [44]. Doctors in training tend
to shy away from careers in surgery because of perceived excessive workloads, low financial returns, a poor learning environment, and the risk of contracting HIV [135].

Uganda has two national referral hospitals—Mulago, in Kampala, and Mbarara, in the southwest—12 regional referral hospitals, and 39 district hospitals [44]. As of 2010, only 51% of health posts were filled by trained health professionals, and only 11% of the population lived within 5 km of a hospital [136]. In addition, despite an abolition of user fees by the Ugandan Ministry of Health, nearly half of healthcare financing comes from out-of-pocket expenditures, households spend 9% of their expenditures on health, and a dual economy of informal payments exists [136].

Cancer causes 11,000 deaths and a loss of 350,000 DALYs annually in Uganda [115]. The incidence-to-mortality ratio in Uganda is approximately 1·26 [116, 117], an indication of the significant dearth of treatment options in the country. To meet this need, a regional cancer center has been proposed in Mbarara, making an evaluation of delivery platforms for surgical oncology a policy-relevant question in this setting.

2·1·4 Agent-based Modeling and Extended Cost-effectiveness Analyses
Multiple policies and platforms, described below, have been promoted for the expansion of surgical care in Uganda. These policies and platforms are likely to have disparate effects on health, impoverishment, and equity.

§ A third referral hospital, Butabika, also in Kampala, serves as the nation’s mental health referral hospital. It is not included in the analyses performed in this chapter, under the assumption that no cancer care of curative intent occurs in this hospital.
An extended cost-effectiveness analysis (ECEA) framework [54-56, 128] is utilized to evaluate these effects. ECEAs have been described in detail in Chapter 1 and in prior work [128], but, briefly, they extend traditional cost-effectiveness techniques to policy-level decisions, with explicit attention paid to the costs of implementation and scale-up, and to impacts on health, impoverishment, and equity.

To date, all published ECEAs have made a significant modeling assumption—that patients are independent of each other. In many cases, this assumption is adequate, but it becomes untenable when policies impact entire populations, and, as will be seen below, when the financial burden of a lack of access is of interest.

Agent-based models (ABMs) have been proposed as realistic models of human-human interactions [137, 138], and have recently been employed to model global health interventions [139]. ABMs allow the modeler to locate patients and platforms within physical space, and to model their interpersonal networks explicitly [140]. By design, these models are stochastic, allowing the easy incorporation of uncertainty.

This chapter, then, has three goals:

- To compare the health, financial, and equity impacts of NGO surgical delivery platforms [113] with governmental policies [136, 141] for surgical oncology in Uganda.
• To propose and evaluate a novel measure of impoverishment that incorporates the familial financial burden of a lack of access to surgical oncology care.

• To provide proof-of-concept evidence that an ABM ECEA is not only a feasible construct for the evaluation of health policy questions, but that it offers benefits above other modeling techniques.

2.2 METHODS

2.2.1 PLATFORMS AND OUTCOMES

This chapter examines nine policies and platforms for surgical oncology delivery in Uganda. Six policies are governmental, and focus on public sector hospitals:

• Universal public financing (UPF), which makes surgery free at the point of care, but does not pay for non-medical costs.

• Task shifting of surgery to non-surgeon providers (TS), which increases the supply of surgical providers but does not address costs.

• UPF + TS—in which non-surgeon providers are trained in surgery, and the medical costs of care are free to the user.

• Combining each of the above policies with vouchers to pay for non-medical costs (UPF + V, TS + V, and UPF + TS + V) [57]

On the non-governmental side, three charitable platforms are examined [113]:

• Two-week surgical “mission trips” (2W)

• Self-contained mobile surgical units (MS)
• Free-standing cancer hospitals (CH)

These platforms are described in more detail below.

The outcomes of interest, also defined in detail below, are the number of deaths averted, cases of catastrophic expenditure averted or created, cases of familial impoverishment averted or created, and societal costs. These outcomes are evaluated per year, per 100,000 in the population, on average and across wealth quintiles.

2.2.2 MODEL DESIGN

2.2.2.1 INDIVIDUAL AGENTS AND POPULATION PARAMETERS

To achieve the aims of this chapter, a synthetic open-cohort Ugandan population of 10,000 individuals was constructed. At instantiation, the starting population was matched to the current age, gender, education, income level, and urban/rural divide of Uganda, derived from the Ugandan 2011 Demographic and Health Survey [142]. Population growth parameters were modeled based on background mortality from published life tables [143]—with tumor-specific mortality backed out—and on published DHS and UN fertility rates [143]. Individual income was drawn from a gamma distribution, parameterized for Uganda [99, 133]. Wealth quintiles were constructed such that, in expectation, 20% of the population fell into each quintile. The dollar-value of the national poverty line was calculated such that 24.5% of the population fell below it [133, 136].
Individuals were placed on a map of Uganda stochastically, with the probability of occupying any latitude/longitude combination proportional to the population density at that latitude and longitude in Uganda [144], and were connected into family-level networks, including parents, spouses, and children if they existed [137, 138]. Each individual was also connected to a simulated “village,” using a distance-based network. On migration and/or death, these connections were broken and re-established, as appropriate.

Except at model instantiation, individuals entered the population at birth. Pediatric cancers were not modeled; as a result, an individual only faced baseline mortality during the first fifteen years of life. On reaching adulthood, each individual agent was modeled as shown in Figure 2·1. While healthy, an individual was allowed to migrate within or out of Uganda. Males in the population sought wives among unmarried women in their networks. Women had children at an exponential rate, such that the average family size in the model was 5 [145]. The total fertility rate was not directly input into the model and was, instead, used as a validation metric.

Sensitivity analyses were performed on model assumptions (see below). Population, cost, and outcome parameters are given in Table 2·1.
Mean values and distributions used in sensitivity analysis. Values for which no distribution is given were not varied across simulation runs. All costs are corrected to 2010 US dollars. USD = US dollar. UGX = Ugandan shillings. Costs of surgical platforms amortize fixed costs over the lifetime of the policy. †Varied at the hospital level. ‡Varied at the simulation level. §Varied at the individual level. α = Gini / 10.
FIGURE 2-1: An adult male in the Ugandan population.

Each agent remains healthy until he gets cancer (\textit{getCancerM}), at which point he decides whether or not to get care and from where (\textit{TestM} and \textit{seekCareM}). If he chooses not to seek care, he lives with untreated disease (\textit{IdleM}) until he dies. If he seeks care, he travels to get it (\textit{TravelingM} and \textit{TreatmentM}), at which point he faces a risk of complications (\textit{complM}) and of peri-operative mortality (\textit{txDeathM}). If he survives these, he returns to his prior position (\textit{ReturningM} and \textit{HomeM}). In the model, men seek wives (\textit{findWife}); children are born to women and are included in the male network only if that man is a woman’s spouse. Internal migration (\textit{MigratingM}) is allowed. In this figure, cancer death (\textit{CancerDeadM}) is counted when an individual dies of untreated disease (including while traveling to treatment, \textit{cancerDeathM}), dies as a result of treatment (\textit{txDeathM}), or dies as a result of complications due to treatment (unlabeled arrow from \textit{complM} to \textit{CancerDeadM}). Not shown in this figure is the baseline mortality rate faced by every agent in the model.
## 2.2.2.2 Cancer incidence and care-seeking behavior

Cancer incidence was modeled after data from the International Agency for Research on Cancer, a branch of the World Health Organization [116, 117]. The age-adjusted cancer incidence in Uganda is given in Table 2.2. Per 100,000 in the population, men have an average incidence of 175.7, and women 167.4. Cancer rate was modeled to meet this incidence. The outcomes were modeled as outcomes from the seven most common cancers, shown in Table 2.2. This is a simplifying assumption that necessarily omits certain cancers; these cancers are, on average, much rarer and slightly less fatal than the included cancers. The expected bias from this assumption, then, is small.

### TABLE 2.2: Age-adjusted cancer incidence in Uganda

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Incidence / 100,000 M</th>
<th>Incidence / 100,000 F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>48.2</td>
<td>—</td>
</tr>
<tr>
<td>Cervix</td>
<td>—</td>
<td>44.4</td>
</tr>
<tr>
<td>Breast</td>
<td>—</td>
<td>27.5</td>
</tr>
<tr>
<td>Esophagus</td>
<td>24.8</td>
<td>10.4</td>
</tr>
<tr>
<td>Kaposi’s sarcoma</td>
<td>21.8</td>
<td>10.9</td>
</tr>
<tr>
<td>Colorectal</td>
<td>7.7</td>
<td>6.6</td>
</tr>
<tr>
<td>Oral cavity</td>
<td>4.8</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>All cancers</strong></td>
<td><strong>175.7</strong></td>
<td><strong>167.4</strong></td>
</tr>
</tbody>
</table>

Source: [116, 117].

If an individual gets cancer, he has to decide whether and where to seek care. This was modeled based on a utilization function for healthcare in Uganda published as a white paper in 2006 [169]. Conditional on getting sick, the utility for the agent, i, seeking care at hospital j, was calculated as follows:
\[ U_{ij} = \alpha + \beta X_i + \gamma Q_j + \delta D_{ij} + \lambda c(Y_i - P_j) + \varepsilon_{ij} \]  

(2.1)

where \( X_i \) represents a vector of individual and household characteristics. \( Q_j \) represents a vector of indicators of quality for facility \( j \), and \( D_{ij} \) is the distance from the agent to the facility. The error term follows a standard Gumbel type 1 distribution [170], and coefficient vectors for all other independent variables are taken from previously published surveys in Uganda [169]. These coefficients were varied stochastically, using beta distributions for all values between 0 and 1, and uniform distributions for coefficient values greater than 1.

The cost function was non-linear, to allow for price elasticities to vary with income. Specifically,

\[ c(Y_i - P_j) = \eta_1 \ln(Y_i - P_j) + \eta_2 [\ln(Y_i - P_j)]^2 \]  

(2.2)

The value function \( V_{ij} \) is the deterministic portion of \( U_{ij} \)—that is, \( V_{ij} = U_{ij} - \varepsilon_{ij} \)—and the value for \( V_{i0} \) (representing the condition in which individual \( i \) chooses not to seek care) was normalized to 0. With this construction, choice probabilities follow a nested multinomial logit model, in which the first choice is whether to seek care at all, and, if so, whether to do so from a public provider or an NGO. Conditional on choosing to seek care, the actual location was chosen by recalculating the value function for each of the
possible providers within the chosen nest (public or private). Following Ssewanyana [169], an individual chose to forgo care with the following probability:

\[
P(j = 0) = \frac{\exp(V_{i0})}{\exp(V_{i0}) + \left[ \sum_j \exp\left( \frac{V_{ij}}{\sigma} \right) \right]^\sigma}
\]  

(2.3)

and chose between public- and NGO-provided care with probability

\[
P(j = K) = \frac{\exp\left( \frac{V_{iK}}{\sigma} \right) \left[ \sum_{j \neq K} \exp\left( \frac{V_{ij}}{\sigma} \right) \right]^{\sigma-1}}{\exp(V_{i0}) + \left[ \sum_j \exp\left( \frac{V_{ij}}{\sigma} \right) \right]^\sigma}
\]  

(2.4)

where sigma represents the in-nest correlation.

If an individual chose not to seek care, she remained in her location and faced a cancer-specific untreated mortality rate [161-163]. If she chose to seek care, she traveled to the location of the chosen provider. Because of the large network of roads and buses in Uganda, 80% of individuals were assumed to travel by vehicular transport and the remaining walked. This likely underestimates the actual time necessary to reach care, with a consequent bias of the results toward the null. At any point before care was actually rendered, the individual faced a cancer-specific untreated mortality rate. Once she arrived at the location, she underwent treatment. Treatment length averaged 14 days, with the actual treatment completion date drawn from a geometric distribution. While
under treatment, the individual faced success, mortality, and complication rates that varied by the level of the hospital at which care was received and whether the provider was a surgeon or a task-shifted provider. Conditional on surviving treatment, the individual then returned to her original position. Of note, recurrences were not explicitly modeled.

2.2.2.3 HEALTHCARE DELIVERY IN THE STATUS QUO
The 53 known national, regional, and district-level hospitals were located on the map, utilizing latitude and longitude data from previously published data [44] and from Google maps (Google, Inc; California, USA). If the exact location of the district hospital could not be found, the latitude and longitude of the geographic center of its containing town were utilized. The two national hospitals (Mulago and Mbarara) were included in this model. Hospital quality metrics were derived from previously published data [44]. Because the quality score in the utility function above is out of eight possible points, the derived hospital quality score was also scaled to a maximum of eight.

The cost of all surgical procedures in Uganda is not available. The only surgical procedure for which data exist is Caesarian section [146]. Although this is likely an underestimate for cancer surgery, it was used as the cost of surgery in the absence of other costs; the actual cost was drawn from a very wide distribution around this average number. If this cost is truly an underestimate, catastrophic expenditure at baseline would be underestimated, thereby underestimating the financial impact of any policy which
removes medical costs, including many of the NGOs. The financial impact of task shifting is difficult to predict—an underestimate of the cost of surgery would overestimate the induced demand by task shifting, but the amount of catastrophic expenditure *conditional* on care-seeking would be underestimated.

Non-medical costs of care access (including the costs of transportation, lodging, and food) were calculated as a multiple of the medical cost, following data from several sources [13-24]. Indirect costs (for example, lost wages) were not included. On average, 49.3% of health expenditure in Uganda is out-of-pocket [133, 136], not including non-medical costs. At baseline, individuals were assumed to incur 49.3% of the medical cost of any intervention, in expectation, and 100% of the non-medical costs. The remaining 50.7% of medical costs were accounted to the government. The actual out-of-pocket proportion of medical costs was drawn stochastically from a beta distribution.

### 2.2.2.4 Policy and Platform Parameters

For policies that included universal public financing (UPF), the full burden of medical costs was transferred to the government; individuals paid nothing out-of-pocket for these costs but were still responsible for non-medical costs. Policies that included vouchers transferred the non-medical costs to the governmental sector but did not affect medical costs. For task shifting, an additional surgical provider was added to each of the district and regional referral hospitals in the country—a change that was reflected in the quality vector above. The scale-up and maintenance costs of a program of task shifting are given
in Table 2.1. These costs come from Mozambique [39], a country of similar population size, and include the costs of training, including libraries, books, and computers, and the salaries of task shifted providers.

The costs faced by a patient seeking care at a regional or district hospital or from a task-shifted provider were assumed to be lower than those from a specialist surgeon [51, 128]. Controversy exists about how the outcomes of care from a task-shifted provider compare to those from a trained surgeon [51, 128]. To remain conservative, complication and mortality rates were assumed to be slightly higher, as in Chapter 1. This assumption would bias the health benefit from task shifting toward zero. Similar to the above, its effect on catastrophic expenditure is uncertain—utilization may be over- or under-estimated, depending on the relative elasticities for price and quality by wealth quintile.

Combinations of the three governmental policies were also included, leading to a total of six governmental policies: UPF, task shifting (TS), UPF + TS, UPF + vouchers (V), TS + V, and UPF + TS + V.

Platforms of surgical delivery by non-governmental organizations were modeled after published data. The “surgical mission trip” (2W) was modeled as a trip to one of the district hospitals [113]. In keeping with previously published data [171-173], the complication rates achieved by these trips were made equivalent to those found at a regional hospital. Trips lasted on average two weeks [113], and recurred on average twice a
year. Trip arrival and departure times were drawn randomly from a geometric distribution parameterized to yield these average results. The costs of each trip are given in Table 2-1 and include the costs of maintaining a sending organization as well as the opportunity costs of individuals going on these trips (measured as their deferred salaries) [164-167].

The mobile surgical unit (MS) was modeled after a similar surgical organization in Ecuador [168]. These costs are extremely small compared to the costs of many other policies. As a result, costs from similar organizations that provide mobile surgical platforms [113] were extracted from their IRS Form 990s and used as sensitivity analyses. This mobile surgical unit was assumed to travel to a different location in Uganda every three months, on average. As with the surgical mission trip, the time of departure from each location was drawn from a geometric distribution whose mean was three months.

Finally, the construction of a cancer hospital (CH) at Mbarara was modeled, as is currently proposed (W. Williams, personal communication). Costs were modeled after the construction costs of an NGO hospital in Haiti (unpublished data). The construction costs were amortized over the fifty-year model run. Salaries, education costs, and upkeep accrued yearly.

Reported surgical cases done per year (or per trip) for the reference NGOs were extracted from the literature when available [168], or from annual reports of the reference
organizations. These were used to calculate a cost-per-case. Although this assumes that amortized fixed costs scale linearly with the number of cases done—which is incorrect—the results of such an assumption would bias the benefit-per-cost for any NGO platform toward the null.

2.2.2.5 Outcomes
Each policy was run 100 times, over 50 years, with a starting population of 10,000 individuals. The model cycled daily. Accounting for population growth, then, results for the status quo and for the modeled policies were each derived from approximately $2.7\cdot10^{12}$ trillion person-years of observation.

Health benefits were measured as the number of deaths averted. Catastrophic expenditure was counted when individuals spent more than 10% of their pre-health-shock expenditure [6] to access care. Impoverishment was measured as a joint outcome: individuals were counted as impoverished if their expenditure pushed them below the national poverty line or if they were in a family whose head of household succumbed to his or her cancer. The system costs and outcomes for delivery under the status quo were calculated first; the results presented below are incremental over the status quo baseline. That is, the total deaths averted by UPF, $TDA_{UPF}$, is the difference between the deaths experienced under UPF and those experienced in the absence of any policy:
\[ TDA_{UPF} = \frac{1}{Y} \left[ \sum_{y} \sum_{i} D_{i,y,\text{SQ}} - \sum_{y} \sum_{i} D_{i,y,\text{UPF}} \right] \tag{2-5} \]

where \( y \) represents each year, \( Y \) represents the total number of years, \( i \) represents individuals in the population, and \( D_{i,y,p} \) represents an indicator which takes the value of 1 if individual \( i \) died in year \( y \) under policy \( p \). Incremental benefits for each of the policies and for each of the measured benefits and costs were calculated identically. All outcomes were counted for the population as a whole, and by wealth quintile.

In addition to representing the equitable distribution of outcomes graphically, a concentration index was constructed for each of the benefits. Concentration indices measure the cumulative proportion of a benefit accrued by cumulative proportions of the population. The best-known concentration index—and the after which the following was modeled—is the Gini index [174].

In this model, income quintiles were normalized such that they each contained 20% of the population in expectation. The concentration index was calculated as a segmental (trapezoidal) approximation of what would otherwise be a continuous distribution:

\[ G = 1 - \left[ \frac{0 \cdot 2}{B_T} \sum_{k=1}^{5} \sum_{j=1}^{k-1} (B_j + B_k) \right] \tag{2-6} \]
where $B_j$ is the benefit of interest, accrued by quintile $j$, $B_T$ is the total benefit accrued across the entire population, and $B_0 = 0$. In cases in which some quintiles had negative impacts while others saw benefits (e.g., some quintiles faced increased catastrophic expenditure while others derived financial risk protection), $B_j$ was standardized such that $\min B_j = 0$, with the remaining benefits scaled commensurately upward. In this formulation, perfect equality is represented by $G = 0$, perfectly pro-poor policies by $G = 1$, and perfectly pro-rich policies by $G = -1$.

### 2.2.2.6 Validation and Sensitivity Analyses

In the base case, the model took the societal perspective, with outcomes as yearly averages per 100,000 individuals.

The model was validated against the following known metrics: population density, predicted 2050 national population, wealth quintile construction, cancer incidence, and cancer incidence-to-mortality ratio. Utilization was also validated by location and by wealth quintile.

Heterogeneity is inherent to an agent-based model, and probabilistic sensitivity analysis distributions are given in Table 2·1. In addition to addressing the uncertainty with parameter variation and heterogeneity, four other sensitivity analyses were performed.
In the first sensitivity analysis, the perspective was changed to that of the Ministry of Health. For the Ministry, the NGOs are essentially cost-less. In the model, NGO costs were assumed to be exogenous to the country itself, while the benefits accrued directly to the population.

As mentioned above, the costs of the mobile surgical platform are significantly smaller than the costs of other policies and platforms. As a result, with the second sensitivity analysis, costs from other NGOs that man mobile surgical units were used [113], as derived from their IRS filings.

The base-case measure of impoverishment counts as impoverished any member of a family whose head of household succumbed to his or her cancer. This is relatively aggressive. In a third sensitivity analysis, a synthetic poverty line was constructed by multiplying the GDP/capita-calculated poverty line in the base case by the average family size in each simulation. In this sensitivity analysis, family members were impoverished only if the loss of income from the late head of household was enough to push the entire family’s wealth below this synthetic poverty line.

Finally, the results in the base-case analysis are presented as yearly averages per 100,000 in the population. In the fourth sensitivity analysis, results are instead presented as the sum of a discounted stream of costs and outcomes. The total deaths averted in this sensitivity analysis, then, were calculated as
The model was constructed in Java, using the AnyLogic modeling platform (The AnyLogic Company, St. Petersburg, Russia); data analysis was performed in R v3.0.

2.3 RESULTS
2.3.1 VALIDATION
The model was validated against the following known metrics: population density, predicted 2050 national population, total fertility rate, cancer incidence, and cancer incidence-to-mortality ratio. Utilization was also validated by location and by wealth quintile.

2.3.1.1 POPULATION DENSITY
The actual and modeled population density of Uganda by geographic location is shown in Figure 2.2. Actual population density is taken from Columbia University’s Gridded Population of the World project [175].
Actual population density [175]

FIGURE 2-2: Actual (top) vs. modeled (bottom) population density in Uganda. In the model, each red and blue dot represents one person.
2.3.1.2 PREDICTED 2050 NATIONAL POPULATION
The Population Reference Bureau predicts that Uganda’s population in 2050 will be 114 million [176]. The distribution of model 100 predictions is shown in Figure 2.3.

![Predicted 2050 population]

**FIGURE 2.3:** Predicted 2050 Ugandan population.
Dashed line = Population Reference Bureau estimate [176]. Shaded region = model output, 100 runs.

2.3.1.3 TOTAL FERTILITY RATE
The United Nations estimates the total fertility rate for Uganda to be 6.38 [143]. The model estimated a total fertility rate of 6.46.
2.3.1.4 Cancer incidence
Published age-adjusted cancer estimates are shown in Table 2.2. Overall, the projected incidence of cancer in Uganda is 171 cases per 100,000 individuals [116, 117]. Figure 2.4 shows the distribution of model predictions of cancer incidence.

**FIGURE 2.4:** Cancer incidence per 100,000.
Dashed line = IARC estimate [116, 117]. Shaded region = model output, 100 runs.
2.3.1.5 Incidence-to-Mortality Ratio
The calculated incidence-to-mortality ratio from published data is approximately 1.268 in Uganda [116, 117]. Figure 2.5 shows the distribution of model predictions.

**FIGURE 2.5:** Incidence : mortality ratio for cancer in Uganda. Dashed line represents published rates (1.268). The mean from the model is 1.26, and the distribution is represented above.
2.3.1.6 Utilization by location and wealth
Utilization is influenced by multiple factors, including wealth and distance to the nearest provider [169]. Figure 2.6 shows baseline utilization of services by wealth quintile, and Figure 2.7 shows the location of the district, regional, and national referral hospitals, juxtaposed with the probability of utilizing care given a cancer diagnosis. The distributions of location, urban/rural living situation, and wealth are not independent, however—individuals living in northern Uganda, for example, tend to be poorer and more rural than those in central Uganda—and utilization depends on the joint distribution of the three. This is shown in Figure 2.8.

As expected, the implementation of any policy or platform increased both access to care and the incidence-to-mortality ratio from cancer. Policies that included vouchers for non-medical costs, and two of the NGO platforms (MS and CH) increased these outcomes significantly. The remainder did not (see Table 2.3).
FIGURE 2·6: The probability of health utilization by wealth quintile. Dashed lines represent the mean utilization by individuals in each wealth quintile, conditional on getting cancer. The distributions represent 100 runs of the model.
FIGURE 2.7: Hospital locations in Uganda (top) and probability of healthcare utilization given location in the model (bottom). Red = highest, blue = lowest.
FIGURE 2-8: Probability of utilization by location alone (top) and the joint probability of utilization by location, wealth, and urban/rural living (bottom). Red = highest, blue = lowest.
TABLE 2.3: Average incremental results over the status quo, per 100,000 population, per year.

<table>
<thead>
<tr>
<th>Platforms and Policies</th>
<th>UPF</th>
<th>TS</th>
<th>UPF + TS</th>
<th>UPF + TS + V</th>
<th>UPF + 2W</th>
<th>MS</th>
<th>CH</th>
</tr>
</thead>
<tbody>
<tr>
<td>System cost, $1000 / 100K</td>
<td>$3.3*</td>
<td>$0.3</td>
<td>$3.7*</td>
<td>$24.5*</td>
<td>$13.7*</td>
<td>$25.0*</td>
<td>$40.4*</td>
</tr>
<tr>
<td>Cancer deaths averted / 100K:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest Cancer deaths averted / 100K</td>
<td>4.88</td>
<td>-3.66</td>
<td>4.67</td>
<td>51.19*</td>
<td>29.97</td>
<td>51.79*</td>
<td>2.35</td>
</tr>
<tr>
<td>Poor Cancer deaths averted / 100K</td>
<td>5.70</td>
<td>7.07</td>
<td>14.00</td>
<td>29.71</td>
<td>27.94</td>
<td>34.53*</td>
<td>2.56</td>
</tr>
<tr>
<td>Middle Cancer deaths averted / 100K</td>
<td>1.54</td>
<td>4.63</td>
<td>11.17</td>
<td>26.51</td>
<td>17.33</td>
<td>30.05*</td>
<td>-0.14</td>
</tr>
<tr>
<td>Rich Cancer deaths averted / 100K</td>
<td>2.90</td>
<td>6.91</td>
<td>8.70</td>
<td>23.71</td>
<td>13.40</td>
<td>27.14</td>
<td>1.91</td>
</tr>
<tr>
<td>Richest Cancer deaths averted / 100K</td>
<td>-0.07</td>
<td>1.09</td>
<td>5.06</td>
<td>22.59</td>
<td>4.62</td>
<td>24.49</td>
<td>0.64</td>
</tr>
<tr>
<td>Overall Cancer deaths averted / 100K</td>
<td>2.99</td>
<td>3.21</td>
<td>8.72</td>
<td>30.74*</td>
<td>18.65*</td>
<td>33.60*</td>
<td>1.46</td>
</tr>
<tr>
<td>Catastrophic expenditure averted / 100K:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest Catastrophic expenditure averted / 100K</td>
<td>-22.69</td>
<td>-29.28</td>
<td>-57.69</td>
<td>147.65*</td>
<td>-95.51</td>
<td>147.65*</td>
<td>7.49</td>
</tr>
<tr>
<td>Poor Catastrophic expenditure averted / 100K</td>
<td>-13.72</td>
<td>-40.72</td>
<td>-53.88</td>
<td>194.92*</td>
<td>-31.65</td>
<td>194.92*</td>
<td>10.10</td>
</tr>
<tr>
<td>Middle Catastrophic expenditure averted / 100K</td>
<td>-1.98</td>
<td>-45.26</td>
<td>-41.47</td>
<td>225.97*</td>
<td>58.12</td>
<td>225.97*</td>
<td>1.63</td>
</tr>
<tr>
<td>Rich Catastrophic expenditure averted / 100K</td>
<td>16.92</td>
<td>-48.46</td>
<td>-4.47</td>
<td>260.79*</td>
<td>151.61*</td>
<td>260.79*</td>
<td>10.81</td>
</tr>
<tr>
<td>Richest Catastrophic expenditure averted / 100K</td>
<td>42.69</td>
<td>-12.02</td>
<td>41.94</td>
<td>263.83*</td>
<td>202.68*</td>
<td>263.83*</td>
<td>6.10</td>
</tr>
<tr>
<td>Overall Catastrophic expenditure averted / 100K</td>
<td>4.24</td>
<td>-34.75</td>
<td>-23.11</td>
<td>218.63*</td>
<td>57.05</td>
<td>218.63*</td>
<td>7.23</td>
</tr>
<tr>
<td>Impoverishment averted / 100K:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest Impoverishment averted / 100K</td>
<td>-12.57</td>
<td>-76.28</td>
<td>-79.01</td>
<td>516.65*</td>
<td>-19.03</td>
<td>518.63*</td>
<td>12.83</td>
</tr>
<tr>
<td>Poor Impoverishment averted / 100K</td>
<td>10.17</td>
<td>13.90</td>
<td>24.30</td>
<td>34.69</td>
<td>53.03</td>
<td>43.46</td>
<td>-0.30</td>
</tr>
<tr>
<td>Middle Impoverishment averted / 100K</td>
<td>3.34</td>
<td>6.13</td>
<td>19.04</td>
<td>35.51</td>
<td>33.21</td>
<td>36.64</td>
<td>0.40</td>
</tr>
<tr>
<td>Rich Impoverishment averted / 100K</td>
<td>5.51</td>
<td>16.19</td>
<td>16.64</td>
<td>21.39</td>
<td>22.76</td>
<td>28.32</td>
<td>1.46</td>
</tr>
<tr>
<td>Richest Impoverishment averted / 100K</td>
<td>-2.90</td>
<td>-0.65</td>
<td>10.19</td>
<td>10.69</td>
<td>-0.18</td>
<td>9.02</td>
<td>-2.54</td>
</tr>
<tr>
<td>Overall Impoverishment averted / 100K</td>
<td>0.71</td>
<td>-8.14</td>
<td>-1.77</td>
<td>123.79*</td>
<td>17.96</td>
<td>127.21*</td>
<td>2.37</td>
</tr>
<tr>
<td>Increased treatment probability (%):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest Increased treatment probability (%)</td>
<td>5.43</td>
<td>4.93</td>
<td>11.85</td>
<td>39.05*</td>
<td>27.57*</td>
<td>46.46*</td>
<td>1.07</td>
</tr>
<tr>
<td>Poor Increased treatment probability (%)</td>
<td>5.04</td>
<td>6.64</td>
<td>11.07</td>
<td>32.38*</td>
<td>24.80*</td>
<td>40.35*</td>
<td>0.87</td>
</tr>
<tr>
<td>Middle Increased treatment probability (%)</td>
<td>3.01</td>
<td>7.40</td>
<td>11.55</td>
<td>27.68*</td>
<td>22.22*</td>
<td>34.52*</td>
<td>1.20</td>
</tr>
<tr>
<td>Rich Increased treatment probability (%)</td>
<td>3.02</td>
<td>6.03</td>
<td>10.10</td>
<td>22.51*</td>
<td>17.46*</td>
<td>28.30*</td>
<td>0.28</td>
</tr>
<tr>
<td>Richest Increased treatment probability (%)</td>
<td>1.90</td>
<td>5.91</td>
<td>7.94</td>
<td>19.66*</td>
<td>12.85</td>
<td>25.53*</td>
<td>1.09</td>
</tr>
<tr>
<td>Overall Increased treatment probability (%)</td>
<td>3.80</td>
<td>6.30</td>
<td>10.68</td>
<td>28.25*</td>
<td>20.98*</td>
<td>35.03*</td>
<td>0.90</td>
</tr>
<tr>
<td>Incidence-to-mortality ratio:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorest Incidence-to-mortality ratio</td>
<td>0.03</td>
<td>0.02</td>
<td>0.03</td>
<td>0.33*</td>
<td>0.17*</td>
<td>0.33*</td>
<td>0.02</td>
</tr>
<tr>
<td>Poor Incidence-to-mortality ratio</td>
<td>0.08</td>
<td>0.08</td>
<td>0.16</td>
<td>0.27*</td>
<td>0.33*</td>
<td>0.50*</td>
<td>0.02</td>
</tr>
<tr>
<td>Middle Incidence-to-mortality ratio</td>
<td>0.05</td>
<td>0.08</td>
<td>0.14</td>
<td>0.42*</td>
<td>0.22</td>
<td>0.51*</td>
<td>0.03</td>
</tr>
<tr>
<td>Rich Incidence-to-mortality ratio</td>
<td>0.03</td>
<td>0.09</td>
<td>0.11</td>
<td>0.40*</td>
<td>0.17</td>
<td>0.47*</td>
<td>0.02</td>
</tr>
<tr>
<td>Richest Incidence-to-mortality ratio</td>
<td>0.01</td>
<td>0.04</td>
<td>0.08</td>
<td>0.48*</td>
<td>0.08</td>
<td>0.54*</td>
<td>0.04</td>
</tr>
<tr>
<td>Overall Incidence-to-mortality ratio</td>
<td>0.04</td>
<td>0.05</td>
<td>0.11</td>
<td>0.40*</td>
<td>0.19*</td>
<td>0.47*</td>
<td>0.03</td>
</tr>
</tbody>
</table>

UPF = universal public financing, TS = task shifting, V = vouchers, 2W = two-week mission trip, MS = mobile surgical platform, CH = cancer hospital. * = p < 0.05.
2.3.2 Governmental platforms
If the NGO sector is excluded, cancer deaths are efficiently averted by TS, UPF + TS, and UPF + TS + V. Catastrophic expenditure is only efficiently averted by UPF + V, while UPF + TS + V is the dominant strategy to avert impoverishment (Figure 2.9). Incremental cost-effectiveness ratios (ICERs) are given in Table 2.4.

**TABLE 2.4**: Incremental cost-effectiveness ratios (ICERs) for governmental policies, non-governmental platforms, and both, in dollars per case averted.

<table>
<thead>
<tr>
<th></th>
<th>Incremental cost-effectiveness ratios</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Deaths</td>
</tr>
<tr>
<td><strong>Governmental policies</strong></td>
<td></td>
</tr>
<tr>
<td>TS</td>
<td>$88.65</td>
</tr>
<tr>
<td>UPF + V</td>
<td>—</td>
</tr>
<tr>
<td>UPF + TS</td>
<td>$631.41</td>
</tr>
<tr>
<td>UPF + TS + V</td>
<td>$662.35</td>
</tr>
<tr>
<td><strong>Non-governmental organizations</strong></td>
<td></td>
</tr>
<tr>
<td>MS</td>
<td>$154.78</td>
</tr>
<tr>
<td><strong>All policies and platforms</strong></td>
<td></td>
</tr>
<tr>
<td>TS</td>
<td>$88.65</td>
</tr>
<tr>
<td>MS</td>
<td>$160.29</td>
</tr>
<tr>
<td>UPF + V</td>
<td>—</td>
</tr>
<tr>
<td>UPF + TS + V</td>
<td>$6022.33</td>
</tr>
</tbody>
</table>

A long dash signifies that the policy is dominated by other policies for that outcome. Strategies dominated in all three columns are not shown. TS = task shifting, UPF = universal public finance, V = vouchers, MS = mobile surgical unit, CH = cancer hospital.
Figure 2.9 continues on the following page.
incremental cost-effectiveness ratios are given in the text. TS, UPF + TS, and UPF + TS + V are efficient at preventing death. UPF + V is efficient at preventing catastrophic expenditure and UPF + TS + V at preventing impoverishment. UPF = universal public financing, TS = task shifting, V = vouchers.

Acceptability curves are shown in Figure 2-10. TS is most likely to be cost-effective if Uganda is willing to pay less than $525 per life saved, $82 per case of catastrophic expenditure averted, or $165 per case of impoverishment averted. If Uganda is willing to pay more than $855 per life saved or more than $470 per case of impoverishment, then UPF + TS + V is preferred. If it is willing to pay more than $82 to avert a case of catastrophic expenditure, UPF + V is preferred.

FIGURE 2.9: Efficiency frontiers for governmental policies.
Figure 2-10 continues on the following page
FIGURE 2.10: Acceptability curves for governmental policies alone. Willingness-to-pay thresholds at which the preferred strategy changes are marked by dashed lines. UPF = universal public financing, TS = task shifting, V = vouchers.

2.3.3 NGO PLATFORMS
Under base case assumptions, MS is the only efficient NGO strategy (Table 2.4 and Figure 2.11). It provides benefits at a cost of $155 per life saved, $66 per case of catastrophic expenditure, and $62 per case of impoverishment averted.
Figure 2.11 continues on the following page.
FIGURE 2·11: Efficiency frontiers for NGO platforms.
For all outcomes, the mobile surgical unit dominates. Of the remaining two, the two-week mission trip is dominated. MS = mobile surgical unit. CH = cancer hospital. 2W = two-week surgical mission

2·3·4 All policies and platforms
If a decision-maker is willing to consider both governmental and NGO policies, only MS is efficient at providing all three benefits of interest. In addition, TS is efficient at preventing cancer deaths; UPF + V is efficient at preventing catastrophic expenditure; and UPF + TS + V can efficiently prevent impoverishment (Table 2·4 and Figure 2·12). MS is preferred as long as Uganda is willing to pay more than $525 to save a life, between $40 and $910 to prevent a case of impoverishment, and between $32·50 and $125 to prevent a case of catastrophic expenditure. Other thresholds are given in Figure 2·13.
Figure 2.12 continues on the following page
FIGURE 2·12: Efficiency frontiers for all policies and platforms.
For all outcomes, the mobile surgical unit dominates. Of the remaining platforms, only the cancer hospital and UPF + TS + V are on the efficiency frontier. The remaining policies are dominated. UPF = universal public finance. TS = task shifting. V = vouchers. MS = mobile surgical unit. CH = cancer hospital. 2W = two-week surgical mission

2·3·5 ECEA PANEL
Deciding among multiple policies across multiple outcomes can be difficult. To aid in decision-making, Figure 2·14 standardizes outcomes against the cost of each policy. Policies toward the upper-right are the most efficient at delivering benefit per dollar. In this formulation, MS is the dominant policy, although TS can also be considered efficient, if society is willing to trade impoverishment for the prevention of cancer deaths.
Figure 2.13 continues on the following page.
FIGURE 2-13: Acceptability curves for all policies and platforms.

Willingness-to-pay thresholds at which the preferred strategy changes are given as dashed lines. UPF = universal public finance. TS = task shifting. V = vouchers. MS = mobile surgical unit. CH = cancer hospital.
FIGURE 2.14: Health vs. catastrophic expenditure (top) or impoverishment (bottom), per $100,000 spent.

Policies closest to the upper right are most efficient. Note that negative cases of catastrophic risk protection and impoverishment averted implies cases created by the respective policies. UPF = universal public finance. TS = task shifting. V = vouchers. MS = mobile surgical unit. CH = cancer hospital. 2W = two-week surgical mission.
2.3.6 EQUITY

Figure 2.15 expands on Figure 2.14 by showing the distribution of cost-standardized health and financial benefits for each of the nine policies and platforms by wealth quintile. This equitable distribution is summarized in the equity index given in Table 2.5, in which a more positive value indicates a more pro-poor outcome distribution. The most pro-poor policies are UPF + V and UPF + TS + V. All NGO platforms also demonstrate a pro-poor distribution. The remaining policies tend to provide more benefit to the rich.

### TABLE 2.5: Equity index of benefits, a measurement of how pro-poor an intervention is

<table>
<thead>
<tr>
<th></th>
<th>Equity index</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Deaths</td>
</tr>
<tr>
<td>Governmental policies</td>
<td></td>
</tr>
<tr>
<td>UPF</td>
<td>0.332</td>
</tr>
<tr>
<td>TS</td>
<td>-0.109</td>
</tr>
<tr>
<td>UPF + TS</td>
<td>0.041</td>
</tr>
<tr>
<td>UPF + V</td>
<td>0.164</td>
</tr>
<tr>
<td>TS + V</td>
<td>0.280</td>
</tr>
<tr>
<td>UPF + TS + V</td>
<td>0.148</td>
</tr>
<tr>
<td>Non-governmental organizations</td>
<td></td>
</tr>
<tr>
<td>2W</td>
<td>0.203</td>
</tr>
<tr>
<td>MS</td>
<td>0.150</td>
</tr>
<tr>
<td>CH</td>
<td>0.044</td>
</tr>
</tbody>
</table>

The more positive the number, the higher the concentration of the benefits accruing to the poorest patients. An equity index of 0 would mean a fully equal distribution of benefits. An index of 1 would mean all the benefits accrue to the poorest quintile, while an index of −1 would mean all benefits accrue to the richest quintile. CH = cancer hospital, MS = mobile surgical unit, TS = task shifting, UPF = universal public finance, V = vouchers, 2W = two-week surgical “mission trips”.

90
Figure 2.15 continues on the next page
FIGURE 2-15: Distribution of health benefits (x-axis) and financial risk protection benefits (y-axis) across wealth quintiles for each policy.

All benefits are standardized by $100,000 spent. First panel: catastrophic expenditure; second panel: impoverishment.
2.3.7 Sensitivity analyses

2.3.7.1 Increasing the societal cost of the mobile surgical unit
Mobile surgical platforms vary immensely in cost. To evaluate the sensitivity of the results to this variability, the unit cost per surgery for MS was increased twelvefold, to match the expenses reported to the IRS by another NGO that uses this delivery model. With this large increase, MS remains an efficient strategy at saving lives, with an ICER of $7243; it is the optimal strategy as long as Uganda is willing to pay $5150 for a life saved (not shown). MS is dominated as a strategy to prevent catastrophic expenditure or impoverishment (Figure 2.16).

2.3.7.2 Ministry of Health perspective
From the perspective of the Ministry of Health of Uganda, the non-governmental organizations are free. Their actual costs are exogenous to the Ministry’s budget, and, as a result, including them in a health delivery platform is relatively costless. Results of an analysis from this perspective are given in Figure 2.17. These analyses do not account for downstream costs in terms of dependence on foreign aid with the presence of NGO.

2.3.7.3 Re-imagining familial impoverishment
The model findings are robust to how impoverishment is calculated. With a more conservative definition of impoverishment, results are unchanged from those in the base-case scenario.
**Discounting of Future Costs and Benefits**

Results are presented in Table 2-6 as a discounted sum of a stream of benefits and costs (with a discount rate of 3% annually). As can be seen from Figure 2-18 and Figure 2-19, the cost-effectiveness relationships of various policies do not actually change.

**Table 2-6**: Incremental costs and benefits above status quo, presented as the discounted sum of a fifty-year stream.

<table>
<thead>
<tr>
<th>Platforms and Policies</th>
<th>UPF</th>
<th>UPF + TS</th>
<th>UPF + V</th>
<th>UPF + TS + V</th>
<th>2W</th>
<th>MS</th>
<th>CH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>System cost $1000/100K</strong></td>
<td>$83.3</td>
<td>$7.1</td>
<td>$91.9</td>
<td>$602.2</td>
<td>$343.5</td>
<td>$61.9</td>
<td>$1,021.3</td>
</tr>
<tr>
<td><strong>Cancer deaths averted / 100K</strong></td>
<td>121</td>
<td>178</td>
<td>333</td>
<td>676</td>
<td>685</td>
<td>784</td>
<td>56</td>
</tr>
<tr>
<td>Poor</td>
<td>138</td>
<td>-82</td>
<td>120</td>
<td>1396</td>
<td>791</td>
<td>1382</td>
<td>55</td>
</tr>
<tr>
<td>Middle</td>
<td>23</td>
<td>101</td>
<td>269</td>
<td>601</td>
<td>417</td>
<td>683</td>
<td>-18</td>
</tr>
<tr>
<td>Rich</td>
<td>55</td>
<td>184</td>
<td>181</td>
<td>500</td>
<td>308</td>
<td>577</td>
<td>34</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>65</td>
<td>80</td>
<td>200</td>
<td>722</td>
<td>453</td>
<td>782</td>
<td>22</td>
</tr>
<tr>
<td><strong>Catastrophic expenditure averted / 100K</strong></td>
<td>467</td>
<td>-1260</td>
<td>-69</td>
<td>6841</td>
<td>4106</td>
<td>6841</td>
<td>336</td>
</tr>
<tr>
<td>Poor</td>
<td>-628</td>
<td>-657</td>
<td>-1466</td>
<td>3633</td>
<td>-2790</td>
<td>3633</td>
<td>206</td>
</tr>
<tr>
<td>Middle</td>
<td>-320</td>
<td>-1063</td>
<td>-1406</td>
<td>5060</td>
<td>-957</td>
<td>5060</td>
<td>278</td>
</tr>
<tr>
<td>Rich</td>
<td>-76</td>
<td>-1156</td>
<td>-1065</td>
<td>5895</td>
<td>1514</td>
<td>5895</td>
<td>11</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>114</td>
<td>-887</td>
<td>-563</td>
<td>5650</td>
<td>1457</td>
<td>5650</td>
<td>190</td>
</tr>
<tr>
<td><strong>Impoverishment averted /100K</strong></td>
<td>230</td>
<td>384</td>
<td>614</td>
<td>840</td>
<td>1359</td>
<td>1051</td>
<td>-8</td>
</tr>
<tr>
<td>Poor</td>
<td>227</td>
<td>-1840</td>
<td>-1952</td>
<td>13703</td>
<td>-480</td>
<td>13654</td>
<td>436</td>
</tr>
<tr>
<td>Middle</td>
<td>20</td>
<td>105</td>
<td>460</td>
<td>934</td>
<td>826</td>
<td>912</td>
<td>-38</td>
</tr>
<tr>
<td>Rich</td>
<td>84</td>
<td>442</td>
<td>330</td>
<td>460</td>
<td>501</td>
<td>616</td>
<td>-40</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>6</td>
<td>-180</td>
<td>-60</td>
<td>3219</td>
<td>415</td>
<td>3262</td>
<td>46</td>
</tr>
</tbody>
</table>

Results presented per 100,000 people. Discount rate = 3%. UPF = universal public finance. TS = task shifting. V = vouchers. 2W = short-term mission trips. MS = mobile surgical units. CH = cancer hospital. Negative cases of impoverishment or catastrophic expenditure averted imply cases created by the policy.
Figure 2.16 continues on the following page.
FIGURE 2.16: Efficiency frontiers for all policies and platforms, under the assumption of increased MS cost.

MS remains on the efficiency frontier as a measure to improve health, but is no longer efficient for financial risk protection or impoverishment prevention. UPF = universal public finance. TS = task shifting. V = vouchers. MS = mobile surgical unit. CH = cancer hospital. 2W = two-week surgical mission
FIGURE 2-17: Standardized health and catastrophic expenditure protection benefits of the six governmental policies and three NGO platforms from the standpoint of the Ministry of Health.

Policies to the upper right are preferred. All governmental platforms are concentrated near the origin. From left-to-right, the three NGO platforms are two-week trips, a cancer hospital, and a mobile surgical unit. UPF = universal public finance, TS = task shifting, V = vouchers.
Figure 2-18 continues on the following page
FIGURE 2.18: Efficiency frontiers when results are presented as discounted streams instead of yearly averages. No difference is noted between these results and the base case.
FIGURE 2-19: Health vs. financial risk protection when results are presented as discounted streams instead of yearly averages.

No difference is noted between these graphs and the base case results.
2.4 DISCUSSION
Health systems must do more than simply improve health: they must provide financial risk protection and do so equitably [11]. Traditionally, policymakers have looked to the public sector to accomplish these aims, because the non-governmental sector has been considered too expensive, inefficient, and dependency-generating [177].

2.4.1 COMPARING NGO PLATFORMS TO GOVERNMENT POLICIES
The results of this analysis indicate that the exclusion of NGOs may be unwarranted. In the setting of surgical oncology in Uganda, the only governmental policies that could provide health benefits, protection against impoverishment, and equity were those that simultaneously addressed the lack of surgical supply, the out-of-pocket medical costs of a procedure, and the oft-ignored non-medical costs necessary to get to care. Policies that addressed each of these barriers alone were largely inefficient.

This is not a surprising finding—to accomplish the disparate goals of a health system, the entire health system must be strengthened. Notably, however, achieving these benefits in a way that does not increase inequity (as can be seen in Table 2.5) may require interventions that cost twice Uganda’s GDP per capita per unit of benefit, and, unless they also address the costs of lodging, transportation, and food inherent in seeking care, still remain insufficient.

Some NGO delivery platforms appear able to provide the same benefits, more efficiently. A mobile surgical unit is able to avert cancer deaths, catastrophic expenditure, and
impoverishment efficiently, and at an incremental cost of $60 – $160 per unit of benefit, and to do so preferentially for the poor. In fact, all three examined NGO delivery platforms demonstrated a pro-poor distribution of benefits.

Not all NGOs are efficient, however. Specifically, the most common surgical NGO platform—the short-term “mission trip” [113]—is explicitly dominated in all scenarios examined in this model. Other evidence has shown that this platform does not deliver good health results [113]; these results imply that whatever benefits are delivered are done so at relatively high cost. In addition, the mobile NGO chosen for the base-case analysis is an in-country NGO—that is, it is staffed by local physicians, run locally, and does not have a large international presence [168]. When costs for MS are increased to match those of an NGO with a large international presence, MS remains efficient at saving lives, but loses its efficiency in impoverishment, further highlighting that NGOs are not able to take the place of health-systems strengthening.

Notably, also dominated is the commonly used governmental policy of user fee removal. Although this is a relatively easy policy to implement, the results of this analysis suggest that it is inefficient. Adding task shifting and non-medical vouchers to it increases the benefit it provides per dollar.
A NOVEL FAMILIAL IMPOVERISHMENT METRIC

The second goal of this chapter was to propose and evaluate a novel metric for impoverishment that accounts for both the financial burden of accessing surgery and that coming from a lack of access. This new metric takes full advantage of the networking capabilities of an ABM, discussed below, to account for impoverishment faced either when an individual is pushed below the national poverty line by a medical expenditure or when a family breadwinner succumbs to his or her cancer.

Recommendations derived from the catastrophic expenditure metric differ slightly from those derived from this new metric, specifically when governmental policies are examined. The lack of sensitivity of the results to this choice of metric is likely due to the fact that surgical costs in Uganda are high relative to the average income.

However, this new metric helps in explaining the financial burden from task shifting. Although task shifting increases catastrophic expenditure, it could be argued that this increase is simply artifactual: individuals are now spending money to access care they did not have before and are therefore financially better off. The new metric belies that argument—multifactorial impoverishment also increases with task shifting, indicating that increased financial burden is not just from individuals who would have died without care. This finding should be considered in discussions of policies to increase surgical supply.
2.4.3 Agent-based Modeling for Health Policy

The third goal of this paper is to show the benefit of ABMs for global health delivery questions.

By relaxing the assumption, found in many prior policy assessments, that individuals are independent of each other, ABMs have a number of benefits over traditional economic or microsimulation modeling. The first is an ability to place agents in multilevel networks. Without this ability, a comprehensive impoverishment metric such as the one proposed above would be impossible.

Secondly, ABMs allow agents to be placed on a map. This is incredibly important in policies that address surgical supply and those that seek to evaluate temporary or mobile delivery platforms. Distance is often a barrier to care and, without an explicit ability to model the distance a patient has to travel, results from other models are more difficult to contextualize.

In addition, correlation exists between where an individual lives and how wealthy he is. With traditional microsimulation modeling, the modeler can make only broad estimates of this correlation. With ABMs, the joint distribution of location, urban/rural probability, and income, all of which influence the choice to seek care, becomes explicit, as in Figure 2.8.
Finally, ABMs offer an additional, policy-relevant capability, not used in this paper. Agents in ABMs can communicate with each other, allowing information on how one patient fares after being treated at a health facility to be communicated to people within his or her network. Although there is anecdotal evidence that this information may influence health-seeking behavior in entire regions [178], this has never been explicitly modeled.

2.4.4 LIMITATIONS
Like all models, this has limitations. The limitations, however, are not likely to have more than a marginal impact on policy recommendations arising from this model.

All models are limited by data availability. Uganda was specifically chosen because of relatively higher data availability when compared to other sub-Saharan African countries. The cancer incidence in Uganda is, for example, derived from a cancer registry populated from hospital records, pharmacies, laboratories, and death registries. In addition, this model is well calibrated to the measurable and predicted outcomes in Uganda, and the vast majority of biases introduced by modeling assumptions, discussed in Section 2, are predicted to be toward the null. Although this strengthens the conclusions that can be drawn, limitations in data availability must still be recognized in these results.

Secondly, although this model supports the role of NGOs as delivery strategies, it cannot model outcomes such as dependency [179] and does not explicitly model other
externalities of the NGO sector such as “brain drain” and the establishment of parallel markets. These are left for future considerations.

Finally, the persistence of impoverishment into the future is not examined. Financial burden in the model is a one-time event, and recovery is not guaranteed. By measuring the incidence of impoverishment due to cancer, not its prevalence, this chapter does not show the full effects of the examined policies. Because of these limitations, these results must necessarily be viewed as hypothesis-generating, not hypothesis-testing.

This chapter, however, examines the delivery of surgical oncology in a resource-poor setting from multiple perspectives: that of health, of catastrophic expenditure, of familial impoverishment, and of inequity. Surgical delivery and cancer care are both incredibly cost-effective in LMICs, comparing favorably with other public health interventions [164-167, 180-184]. Cost-effectiveness alone does not, however, capture the full range of the patient-centered impacts of care. When health, catastrophic expenditure, familial impoverishment, and equity are considered, these results suggest that only a few of the policies and platforms currently employed—mobile surgical units and governmental policies that strengthen the entire health system and address the non-medical cost of getting to care—are equitable and efficient. The vast majority of NGO platforms and governmental policies provide less benefit, less equitably and at a higher cost. Deciding among these policies in a way that balances the health, expenditure, impoverishment, and equity benefits is the subject of future research.
2.5 CONCLUSION
In cancer patients, an inability to access the surgical system can be lethal, and cost is often a barrier. This chapter demonstrates that NGO-based mobile surgical units are an efficient platform for improving health, protecting against impoverishment, and improving equity. These platforms compare well with comprehensive health-systems-strengthening policies. Other platforms and policies appear not to be efficient and equitable for the scale-up of surgical oncology care. These results are robust to many sensitivity and scenario analyses.
Chapter Three:
TRADING BANKRUPTCY FOR HEALTH IN THE UNITED STATES
ABSTRACT

Background: Healthcare in the United States is expensive and drives nearly two-thirds of national bankruptcy cases. In discussions of care delivery, however, it is often assumed that, when faced with lethal disease, individuals would opt for cure at almost any cost. This assumption has never been tested, and knowledge regarding how the American population values a tradeoff between cure and bankruptcy is unknown.

Methods: A discrete-choice experiment was performed with 2359 members of the US general public. Respondents were asked thirteen questions that required them to value combinations of cure and bankruptcy in the presence of a lethal disease. 600 possible model specifications for preferences were tested and dominant models were averaged. Sensitivity and subgroup analyses were undertaken to test the robustness of the results.

Results: When presented with a choice that involves cure for a lethal disease and a risk of bankruptcy, utility for the American public is multiplicative in the probability of cure and the probability of financial risk protection. Financial risk protection more strongly influences preferences than the cure. This finding was statistically significant. No sensitivity or subgroup analysis flipped the relationship between financial risk protection and cure.

Conclusions: Americans do not follow a cure-at-all-costs rubric. This chapter provides empirical evidence for how the US population values a tradeoff between getting health
and facing bankruptcy; in doing so, it brings the financial burden of healthcare access in the US to the fore.
3.1 INTRODUCTION

Patients seeking medical care face an obvious risk to their health. They also risk impoverishment. In the United States, nearly two-thirds of bankruptcy is medical [7], and insurance is not fully protective: three-quarters of patients facing medical bankruptcy were insured at the time of their catastrophic medical bill. Moreover, nearly all medical debtors carry debt that exceeds one-tenth of their family income [7].

Although this risk falls on all patients, its effect is not distributed equitably: bankruptcy risk is most pronounced among the poor and among patients with life-threatening conditions [8, 9]. Bankruptcy is also increasingly common in older Americans: since the 1990s, the country has seen a steep increase in the number of Americans over the age of 65 years filing for bankruptcy, an increase driven in part by illness [10].

The World Health Organization [11], the UN [12], and the World Bank [13] have all recently renewed calls for the assurance of financial risk protection in health. The former posits that health systems have three objectives: (1) to improve health, (2) to provide financial protection from the high costs of care, and (3) to respond to users’ non-health expectations [11].

Medical impoverishment persists worldwide, however, largely because an ability to pay is not strictly correlated with the willingness to do so [6, 185, 186]. Some patients are willing
to face financial ruin to seek medical care [4-6, 14-28], while, for others, costs drive them not to comply with physician recommendations or to forgo care altogether [29-34].

Choosing policy interventions, then, requires an implicit assumption about preferences. Unfortunately, not only are these preferences unknown, but patients themselves are not often involved in these discussions. This is important: patient preferences—especially those of the elderly and those at the end of life—are notably not the same as those of providers or policymakers. Patients with a terminal cancer diagnosis, for example, are often willing to accept significantly more medically toxic treatments with minimal chances of life extension than are their physicians [187, 188]. Whether they are willing to accept more financially toxic interventions is not clear.

No study, however, has yet evaluated how individuals value these tradeoffs. How much of a risk of bankruptcy people are willing to shoulder to seek care is unknown, nor is it known how things like age, income, family composition, health status, and education influence this decision. This chapter explores these questions.

3.2 METHODS
Discrete-choice experiment (DCE) methodology, described in detail elsewhere [189-191], is employed in this chapter to assess the marginal rate of substitution (MRS) between the chance of a cure and the risk of bankruptcy. The primary hypothesis in this study is that, when cure is on offer, individuals display a strong preference for seeking it and are willing
to trade relatively high risks of financial catastrophe to do so. The corresponding null hypothesis is that individuals value cure and financial risk protection equally. Secondarily, the MRS is hypothesized to vary with age, gender, race and ethnicity, the number of children an individual has, income, education, health status, prior experience with serious disease, and region of the country in which an individual lives.

3.2.1 THEORETICAL UNDERPINNING

3.2.1.1 RANDOM UTILITY MODEL
Discrete choice models treat individuals as utility-maximizers: when presented with two alternatives, individuals choose the alternative providing the highest utility. Formally, let Y represent the choice between two numbered alternatives, 0 and 1. Then:

\[ Y = I(U_1 > U_0) \]

where \( I(\cdot) \) represents an indicator function, taking the value of 1 if the expression in parentheses is true and 0 otherwise.

To deal with the fact that utility is unobservable, random utility models [192, 193] decompose the utility for an individual, \( n \), for an alternative, \( i \), into a deterministic (observable) portion, \( V_{in} \), and a random (unobservable) portion, \( \eta_{in} \), such that the utility for any choice, \( i \), is:**

---

** For ease of representation, an individual-specific subscript, \( n \), will be omitted from this and all following explanatory equations

113
\[ U_i = V_i + \eta_i \]

The experimenter can only observe choices and can therefore calculate probabilities of these choices. The probability that an individual chooses alternative 1 is

\[
P(Y = 1) = \int I(V_1 + \eta_1 > V_0 + \eta_0) f(\eta) d\eta
= \int I(V_1 - V_0 > \eta_0 - \eta_1) f(\eta) d\eta
\]

where \( f(\eta) \) represents the density function of the difference in errors, \( \eta_0 - \eta_1 \). The fact that the absolute value of any one utility cannot be observed implies that the driving force in a discrete choice analysis is the difference in the utilities between two alternatives, and, as a result the model used to evaluate this probability depends on \( f(\eta) \).

The logit model is commonly used, in which the error term follows an extreme-value distribution, independent and identically distributed across decision-makers. This model has the benefit of mathematical simplicity: under logit assumptions, the probability of an individual choosing alternative \( i \) over alternative \( j \) is

\[
P_i = \frac{e^{\nu_i}}{e^{\nu_i} + e^{\nu_j}}
\]
However, the assumption of independence of errors is relatively strong. Other models have been used which allow for the relaxation this assumption: the heteroscedastic logit, first proposed by Bhat in 1995 [194, 195], allows for correlated errors, as does the probit model, which assumes a normal distribution of errors [196]. The latter secondarily imposes another strong assumption, however: because the normal distribution has density on both sides of zero, it must be possible that at least some utilities are negative.

Classically, the deterministic portion of the utility, $V_i$, has been parameterized linearly. Given a set of alternative-specific attributes, $x_i$, and a vector of coefficient weights on each attribute, $\beta$, then

$$U_i = \beta' x_i + \eta_i$$  \hspace{1cm} (3.2)

For exposition, let $x = \{\text{cost, time}\}$, in which case, $U_i = \beta_c C_i + \beta_t T_i + \eta_i$, and Equation (3.1) becomes

$$P(Y = 1) = \int 1(\beta_c(C_1 - C_0) + \beta_t(T_1 - T_0) > \eta_0 - \eta_1)f(\eta)d\eta$$
3.2.1.2 Scaling and sociodemographic variables

The error term has a mean and a variance. Without any loss in generality, it can be decomposed into the sum of a mean-zero random variable and a constant: \( \eta_i = k_i + \varepsilon_i \), allowing equation 3.2 to be re-written:

\[
\begin{align*}
U_0 &= k_0 + \beta_c C_0 + \beta_t T_0 + \varepsilon_0 \\
U_1 &= k_1 + \beta_c C_1 + \beta_t T_1 + \varepsilon_1
\end{align*}
\]

(3.3)

This formulation, however, cannot be fully specified. Specifically, \( k_i \) cannot be observed for each alternative. As such, it is customary to standardize \( k \) for one alternative to zero:

\[
\begin{align*}
U_0 &= \beta_c C_0 + \beta_t T_0 + \varepsilon_0 \\
U_1 &= k^* + \beta_c C_1 + \beta_t T_1 + \varepsilon_1
\end{align*}
\]

(3.4)

where \( k^* = k_1 - k_0 \), and is interpreted as the additional utility a decision maker gets for alternative 1 when it is presented against alternative 0.

As with any regression, controlling for observed confounders is desirable. The same problem with identifiability occurs, however, in the setting of any variable that is inherent to an individual and, therefore, invariant across alternatives. Controlling for sociodemographic covariates in decision makers must therefore be done similarly. In the case of gender, for example, the (non-identifiable) full model would be:
\[ U_0 = k_0 + \beta_c C_0 + \beta_t T_0 + \delta_1 MALE + \epsilon_0 \]
\[ U_1 = k_1 + \beta_c C_1 + \beta_t T_1 + \delta_2 MALE + \epsilon_1 \] (3.5)

Again, the value of the coefficient on \textit{MALE} is standardized such that

\[ U_0 = \beta_c C_0 + \beta_t T_0 + \epsilon_0 \]
\[ U_1 = k^* + \beta_c C_1 + \beta_t T_1 + \delta^* MALE + \epsilon_1 \] (3.6)

and a positive \( \delta^* = \delta_1 - \delta_0 \) is interpreted as the additional utility derived by men from the choice of alternative 1 when compared to alternative 0.

Linear utility models have the benefit of an ease of interpretability of the marginal rate of substitution. In the model above, the MRS between time and cost is simply

\[ \frac{\beta_t}{\beta_c} \] (3.7)

\subsection*{3.2.1.3 Multiplicative utility}

\textit{A priori}, it is difficult to believe that a tradeoff between health protection and financial risk protection is perfectly linear. As such, a multiplicative utility model is developed, after Fosgerau and Bierlaire [197]. Specifically:
Because utility is unique to positive transformations, if $U_1 > U_2$, then $\ln U_1 > \ln U_2$, and

\[
P(Y = 1) = \int I(V_1 \eta > V_0 \eta_0) f(\eta) d\eta
= \int I(\ln V_1 + \ln \eta_1 > \ln V_0 + \ln \eta_0) f(\ln \eta) d(\ln \eta)
= \int I(\ln V_1 - \ln V_0 > \ln \eta_0 - \ln \eta_1) f(\ln \eta) d(\ln \eta)
\]

This formulation brings up three issues that must be addressed. The first is the distribution of error terms, which are now multiplied into the deterministic portion, instead of added to it. A formulation as in Equation (3·9) does not allow for $\eta_i$ to be normally distributed: because the natural logarithm of a negative number is undefined, Equation (3·9) is impossible if $U_i \sim \mathcal{N}(\mu, \sigma)$. This problem can be avoided if utilities are constrained to be strictly positive. As such, the deterministic utility must be specified such that $V_i > 0$.

In this case, evaluation of Equation (3·9) is possible if the logged utilities are distributed normally—implying that the multiplicative utilities could follow a lognormal distribution. Fosgerau and Bierlaire [197] have also shown that using the extreme-value distribution for the logged errors implies that the distribution for the multiplicative utilities is a generalized exponential. That is, if $-\ln \eta = \xi / \lambda$ and $\xi$ is distributed extreme value, then $F_\eta(x) = 1 - e^{-x \lambda}$. 
In this formulation, \( \lambda > 0 \) is a scale parameter, constant across all alternatives. It must either be estimated, or, as is done in this paper without loss of generality, constrained to 1.†† This simplifies the error distribution to an exponential, which, as Fosgerau and Bierlaire note [197], provides maximum entropy (ie, adds minimal information to the deterministic utility) of the strictly-positive distributions. As will be seen in Equations (3·10) and (3·12), below, constraining \( \lambda \) does not affect the MRS and will not alter the directionality of the coefficients on sociodemographic demographic variables.

Controlling for sociodemographic variables must be addressed next. The multiplicative analog to the utility functions given in Equation (3·6) is:

\[
\begin{align*}
U_0 &= \left[ C_0^\beta c T_0^\beta e^{\xi_0} \right]^\lambda \\
U_1 &= \left[ C_1^\beta c T_1^\beta e^{(k^*+\delta^* MALE+\xi_1)} \right]^\lambda
\end{align*}
\]  

(3·10)

As with the linear utility specification, a positive value for \( \delta^* \) increases utility for alternative 1 in men, when compared against alternative 0. In this case, however, \( e^{\delta^*} \) represents the factor in men by which utility for alternative 1 is multiplied when

††As long as \( \lambda \) remains strictly positive (which is required for the normalization in Fosgerau and Bierlaire), and utilities are strictly positive, then \( U_0 > U_1 \) implies that \( (U_0)^\lambda > (U_1)^\lambda \). Although holding \( \lambda \) constant will change the values on each of the estimated coefficients, this is the case with all discrete-choice experiments: the value of any coefficient is subject to normalization against the variance of the error term. Direct comparisons of the magnitude of coefficients between models with \( \lambda \) held constant and those with \( \lambda \) estimated are difficult, but holding \( \lambda \) constant does not change interpretations of the signs on these coefficients.
compared with alternative 0, as opposed to the simple addition of $\delta^*$ seen in Equation (3.6).

Finally, the MRS for the two alternative-specific attributes, $C_i$ and $T_i$, must be determined taking the partial derivatives of $U_1$, with respect to $C_1$ and $T_1$—

$$\frac{\partial u_1}{\partial C_1} = \frac{\lambda \beta_c \left( c_1^{\beta C_i} t_1^{\beta T_i} e^{(k^* + \delta^* MALE + \xi_1)} \right)^\lambda}{c_1}$$

$$\frac{\partial u_1}{\partial T_1} = \frac{\lambda \beta_t \left( c_1^{\beta C_i} t_1^{\beta T_i} e^{(k^* + \delta^* MALE + \xi_1)} \right)^\lambda}{t_1}$$

—the following is marginal rate of substitution:

$$\frac{\partial u_1}{\partial C_1} \frac{\partial C_1}{\partial T_1} = \frac{\beta_c}{\beta_t} \frac{t_1}{c_1}$$

(3.12)

This MRS has the nice property of being independent of $\delta^*, k^*$, and $\lambda$. These parameters influence the MRS only insofar as they control for variation driven by observed covariates in estimations of $\beta_c$, and $\beta_t$ themselves.

3.2.2 Survey Design
DCEs give respondents a choice between two discrete scenarios, differentiated along parameters of interest [190]. In this study, respondents were instructed to imagine that they had a hypothetical condition, lethal without treatment. They were then asked to
choose between two treatments, identical in every way except for their probability of a cure and their risk of driving the individual into bankruptcy (Table 3·1).

**TABLE 3·1: Example discrete choice question**

<table>
<thead>
<tr>
<th>You have a condition that is lethal without treatment.</th>
<th><strong>Treatment A</strong></th>
<th><strong>Treatment B</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Two treatments are available, identical in every way except as shown at right.</td>
<td>50% chance of cure</td>
<td>75% chance of cure</td>
</tr>
<tr>
<td></td>
<td>25% chance of bankruptcy</td>
<td>75% chance of bankruptcy</td>
</tr>
<tr>
<td><strong>Which do you choose?</strong></td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
</tbody>
</table>

Respondents were given explicit definitions of the terms “cure” and “bankruptcy” so as to assure as much consistency as possible in responses. Each of the two probabilities of interest had five levels—10%, 25%, 50%, 75%, and 90%. Because utility assessments are confounded in the presence of certainty [198], and because no realistic medical intervention would have either a 0% or 100% chance of cure, the ends of the scale were not included.
At the start of the survey, respondents were also asked to rank the following four possible outcomes of a hypothetical choice, presented to them in random order: “Cured and Not Bankrupt”, “Cured and Bankrupt”, “Dead and Not Bankrupt”, “Dead and Bankrupt”.

A typical DCE asks respondents 8 to 16 questions [189]; respondents in this study answered 12 such questions. In order to test understanding, the first two choice sets had one obviously dominant alternative. If respondents picked the non-dominant alternative in either of these two questions, they received a prompt alerting them to this fact. They only received this prompt once, however, even if they picked the non-dominant strategy in both validation questions.

Because prior experience with a lethal disease—either as a patient or as the primary caretaker of a patient with a serious disease—and self-reported health are likely to influence one’s preferences, respondents were also asked about these. Demographic data were also collected. A copy of the survey is included in Appendix A.

3.2.3 Study Sample
The survey was initially piloted in two samples of respondents from Cambridge, MA. In the first sample, ten respondents were given a full-factorial version of the survey with all 25 possible discrete-choice pairings. Upon completion, comments were elicited to determine whether the survey itself was understandable. No respondent had difficulty understanding the questions but most complained of fatigue at answering too many.
The second group of 50 respondents took a blocked version of the survey. The purpose of this group was to establish a prior estimate for the MRS, which could then be used in sample-size calculations. These respondents were also allowed to make comments on the survey experience.

The pilot group showed an MRS of 1.8 (linear formulation). Simulation was then performed to determine the sample size required to find an MRS between 1.5 and 2.0 with 80% power. A sample of approximately 1000 respondents was found to be necessary, consistent with formal sample size calculations performed for other valuation studies [189, 190] and recent medical and marketing DCEs [199, 200]. To allow for subgroup analysis, and to allow for error in the initial estimate of the MRS, the desired sample size was increased to 2200.

The final survey was distributed through Knowledge Networks, an internet-based survey research firm that provides online, nationally representative panels [201]. Half of the recruited sample was over 65 to allow for an examination of the effects of Medicare eligibility on preferences; weighting was applied to the full sample to make it nationally representative [201].

3.2.4 Analysis
In the linear formulation, the utility for individual $n$ on an alternative, $j$, was assumed to be:
\[ U_{nj} = k_j + \beta_j X_n + \nu_j VALID_n + \omega_j ORDER_n + \gamma BANK_j + \delta CURE_j + \epsilon_{nj} \] (3.13)

where \( X_n \) represents a matrix of individual demographic characteristics; \( CURE_j \) represents the probabilities of cure for the given alternative; \( BANK_j \) and represents \( 1 - \) its probability of bankruptcy; \( VALID_n \) is an indicator variable, with \( 1 \) indicating that individual \( n \) chose the dominant strategies in the validation questions; and \( ORDER_n \) is similarly an indicator variable, with \( 1 \) indicating that individual \( n \) ranked the four possible choice outcomes in the following order: “Cured and Not Bankrupt”, “Cured and Bankrupt”, “Dead and Not Bankrupt”, “Dead and Bankrupt”.

Individuals were given binary choices. Although the choices were presented at random to each respondent, they were analyzed so that the second alternative provided a strictly higher chance of cure. As such, \( k^*, \beta^*, \alpha^* \) and \( \delta^* \) were standardized as in Equation 3.6 and represent the additional utility a respondent with the corresponding characteristics derives from choosing the option with the higher chance of cure—and therefore, the higher likelihood he or she would be to choose this alternative.

As discussed above, because the linear formulation of utility is unlikely to be strictly true, a multiplicative utility function was also evaluated:

\[ \ln U_{nj} = \lambda \left[ k_j + \beta_j X_n + \nu_j VALID_n + \omega_j ORDER_n + \gamma \ln BANK_j + \delta \ln CURE_j + \epsilon_{nj} \right] \] (3.14)
with $\lambda = 1$. Because $BANK$ and $CURE$ are strictly positive, this formulation constrains $V_{nj} > 0$, which is necessary for model specification, as discussed above.

### 3.2.5 Model and Variable Selection

$X_n$ contained twenty-one demographic variables, all of which could plausibly be associated with an individual’s choice. Because this is the first study to examine an indifference curve between health and bankruptcy in the US, no prior work existed to guide the choice of the functional form of utility or which explanatory variables to include. As a result, 600 possible models were evaluated. Half utilized Equation (3.13) and half Equation (3.14); half again explicitly estimated $k^*$ and half did not. Using the Akaike information criterion for model selection [202], a 95% credibility set of models was constructed [203]. Because no single model dominated the 95% credibility set, a weighted model was then constructed as previously described [204, 205].

Because indifference curves represent the marginal rate of substitution between two alternatives, and because Equations (3.7) and (3.12) have shown that the MRS, after controlling for demographic variation, is independent of demographics, the following indifference curves can be constructed for the linear and multiplicative utility formulations, respectively:

\[
U^0 = \gamma^*BANK + \delta^*CURE
\]  
(3.15)

\[
U^0 = BANK\gamma^* \cdot CURE\delta^*
\]  
(3.16)
where $\gamma^*$ and $\delta^*$ represent the estimated coefficients after controlling for demographics.

The choice of analytic model was driven by a priori considerations of the distribution of utilities in the population. Using a probit model would imply that at least some linear utilities are negative—that is, that some individuals would prefer to be dead and/or impoverished—an assumption that was felt unlikely to be true. (This was confirmed in the analysis below). To avoid this assumption, but also to avoid the independence-of-errors assumption in the classical logit model, a heteroscedastic extreme-value model of choice [194, 195] was employed, with clustering at the individual level.

Statistical analyses were performed in R v3·0, using the mlogit package [206], and in the Biogeme estimation package [207]. This study was deemed exempt by the Institutional Review Board of the Harvard School of Public Health.
3.3 RESULTS

3.3.1 PANEL CHARACTERISTICS

The survey was distributed to 4918 respondents. 2975 returned the survey (response rate: 60.5%). 616 surveys were discarded because they omitted more than one-third of the discrete-choice questions, leaving 2359 surveys on which these analyses were done. Respondent and non-respondent characteristics are given in Table 3.2. The respondents with complete surveys were 1.6 years older than the remainder, were 7% more likely to be male, 2% more likely to identify as the heads of their households, 5% more likely to be married or living with their partners, 10% more likely to have at least a bachelor’s degree, and 15% more likely to identify as white. Respondents with complete surveys had 0.1 fewer children living at home on average than the remainder. Median self-reported income was identical among groups, as were employment outside of the home and the presence of internet access at home.

The median self-reported health of the 2359 respondents was 8, on a scale where 10 represents perfect health. The median age of respondents under 65 was 44; for those over 65, median age was 71. Approximately one-third of participants were from the southern United States. In the two validation choice sets, each with an obviously dominant alternative, 91.2% of respondents picked the dominant choice, 87.1% without prompting, and the remaining after a prompt.
Two-thirds of respondents ranked the possible outcomes in the following order, from most to least preferred: “Cured and Not Bankrupt”, “Cured and Bankrupt”, “Dead and Not Bankrupt”, “Dead and Bankrupt”. The next most common ordering—“Cured and Not Bankrupt”, “Dead and Not Bankrupt”, “Cured and Bankrupt”, “Dead and Bankrupt”—was
chosen by 16.9% of respondents. 5.3% chose “Cured and Not Bankrupt”, “Cured and Bankrupt”, “Dead and Bankrupt”, “Dead and Not Bankrupt”. Finally, 3.9% chose “Cured and Not Bankrupt”, “Dead and Bankrupt”, “Cured and Bankrupt”, and “Dead and Not Bankrupt.” 1% or fewer of the respondents chose each of the remaining rankings. There was no significant difference in self-reported income or number of children in these groups. However, individuals who ranked “Dead and Bankrupt” over “Dead and Not Bankrupt” had lower self-reported health than those who chose the more common ranking (p = 0.001). Similarly, individuals who ranked “Dead and Not Bankrupt” higher than “Cured and Bankrupt” had fewer kids (p = 0.04) and lower self-reported health (p = 0.01) than individuals who held the opposite ranking.

After the ordering question and the two validation questions, respondents were randomized to receiving two of five possible blocks of five discrete choice questions (such that each individual received an additional ten questions). No significant difference was found in the demographics of individuals receiving any of the five blocks (Table 3.3).
TABLE 3·3: Sample balance by block

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Block 1</th>
<th>Block 2</th>
<th>Block 3</th>
<th>Block 4</th>
<th>Block 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>990</td>
<td>920</td>
<td>944</td>
<td>889</td>
<td>975</td>
</tr>
<tr>
<td>Age(^a)</td>
<td>65</td>
<td>65</td>
<td>64</td>
<td>65</td>
<td>63</td>
</tr>
<tr>
<td>Age &gt; 65</td>
<td>0·502</td>
<td>0·507</td>
<td>0·497</td>
<td>0·504</td>
<td>0·484</td>
</tr>
<tr>
<td>Male</td>
<td>0·511</td>
<td>0·535</td>
<td>0·542</td>
<td>0·493</td>
<td>0·523</td>
</tr>
<tr>
<td>HoH</td>
<td>0·843</td>
<td>0·841</td>
<td>0·860</td>
<td>0·862</td>
<td>0·842</td>
</tr>
<tr>
<td>Married</td>
<td>0·648</td>
<td>0·627</td>
<td>0·666</td>
<td>0·666</td>
<td>0·658</td>
</tr>
<tr>
<td>Kids(^a)</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Employed</td>
<td>0·426</td>
<td>0·428</td>
<td>0·436</td>
<td>0·439</td>
<td>0·429</td>
</tr>
<tr>
<td>Bachelors</td>
<td>0·361</td>
<td>0·349</td>
<td>0·369</td>
<td>0·381</td>
<td>0·360</td>
</tr>
<tr>
<td>White</td>
<td>0·820</td>
<td>0·800</td>
<td>0·808</td>
<td>0·782</td>
<td>0·798</td>
</tr>
<tr>
<td>Black</td>
<td>0·060</td>
<td>0·063</td>
<td>0·060</td>
<td>0·074</td>
<td>0·068</td>
</tr>
<tr>
<td>Other</td>
<td>0·043</td>
<td>0·050</td>
<td>0·056</td>
<td>0·069</td>
<td>0·054</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0·077</td>
<td>0·087</td>
<td>0·075</td>
<td>0·075</td>
<td>0·080</td>
</tr>
<tr>
<td>Health(^a)</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Tobacco</td>
<td>0·134</td>
<td>0·125</td>
<td>0·125</td>
<td>0·119</td>
<td>0·127</td>
</tr>
<tr>
<td>Alcohol</td>
<td>0·694</td>
<td>0·705</td>
<td>0·702</td>
<td>0·713</td>
<td>0·686</td>
</tr>
<tr>
<td>Prior</td>
<td>0·226</td>
<td>0·211</td>
<td>0·206</td>
<td>0·180</td>
<td>0·199</td>
</tr>
<tr>
<td>Urban</td>
<td>0·856</td>
<td>0·842</td>
<td>0·849</td>
<td>0·852</td>
<td>0·845</td>
</tr>
<tr>
<td>Northeast</td>
<td>0·181</td>
<td>0·201</td>
<td>0·172</td>
<td>0·180</td>
<td>0·187</td>
</tr>
<tr>
<td>Midwest</td>
<td>0·247</td>
<td>0·221</td>
<td>0·238</td>
<td>0·235</td>
<td>0·236</td>
</tr>
<tr>
<td>South</td>
<td>0·335</td>
<td>0·354</td>
<td>0·367</td>
<td>0·348</td>
<td>0·346</td>
</tr>
<tr>
<td>West</td>
<td>0·236</td>
<td>0·224</td>
<td>0·224</td>
<td>0·237</td>
<td>0·232</td>
</tr>
</tbody>
</table>

None of the above means and medians was statistically significantly different from the others.
\(^a\) = Median. Demographic designations are as in Table 3·2.

3·3·2 Survey results

Of the 600 models tested, 99·9% of the explanatory power came from two models, both of the multiplicative form (Equation (3·14)). Their deterministic specification is listed in Table 3·4. A weighted average of the results from these models was determined as described previously [202]. Results from both the individual models and the averaged
final model are given in Table 3.5, with the responses weighted for national representativeness.

**TABLE 3.4: Model selection**

<table>
<thead>
<tr>
<th>Model number</th>
<th>Included variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$\alpha + \ln(BANK) + \ln(CURE) + Age + Female + Prior + Urban + Married + NumKids + \ln(Inc) + Health + Valid + Understood + HoH + Smoker + Drinker + Northeast + Order$</td>
</tr>
<tr>
<td>2</td>
<td>$\alpha + \ln(BANK) + \ln(CURE) + Age + Female + Prior + Urban + Married + NumKids + \ln(Inc) + Health + Valid + Understood + HoH + Smoker + Drinker + Northeast + Order + White$</td>
</tr>
</tbody>
</table>

$\alpha$ = alternative-specific intercept. BANK = $1$ – probability of bankruptcy. CURE = probability of cure. Married = married or living with partner. Prior = “Have you had or served as a caretaker for someone with a serious disease?” NumKids = number of children. Inc = income. HoH = identifies as the head of household. White = identifies as white, non-Hispanic. Drinker = more than one drink per month. Northeast = location in the Northeastern United States. Health = “How would you rate your current state of health? (0 – 10).” Understood = “How well do you feel you understood this survey? (0 – 10)”. For an explanation of validity (Valid) and of state ordering (Order), see the text. Age, NumKids, Inc, Health, Understood were entered as discrete or continuous variables; the remainder were binary (1 if true, 0 if false).

The societal indifference curve for a tradeoff between a risk of bankruptcy and a chance of cure in the nationally-representative sample is given in Figure 3.1. After controlling for observable covariates, the MRS favors financial risk protection, which can be seen by the relatively flat nature of the indifference curves. The difference in the coefficients on cure and bankruptcy was statistically significant ($p = 0.050$).
TABLE 3.5: Survey results

<table>
<thead>
<tr>
<th></th>
<th>Model 1</th>
<th>Model 2</th>
<th>Weighted Model$^a$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-0.091</td>
<td>-0.112</td>
<td>-0.097</td>
</tr>
<tr>
<td>ln(BANK)</td>
<td>0.633</td>
<td>0.633</td>
<td>0.633***</td>
</tr>
<tr>
<td>ln(CURE)</td>
<td>0.507</td>
<td>0.507</td>
<td>0.507***</td>
</tr>
<tr>
<td>Age</td>
<td>-0.003</td>
<td>-0.003</td>
<td>-0.003</td>
</tr>
<tr>
<td>Female</td>
<td>0.037</td>
<td>0.038</td>
<td>0.037</td>
</tr>
<tr>
<td>White</td>
<td>—</td>
<td>0.036</td>
<td>0.010</td>
</tr>
<tr>
<td>Urban</td>
<td>0.104</td>
<td>0.109</td>
<td>0.105</td>
</tr>
<tr>
<td>Married</td>
<td>-0.111</td>
<td>-0.112</td>
<td>-0.111</td>
</tr>
<tr>
<td>NumKids</td>
<td>-0.033</td>
<td>-0.033</td>
<td>-0.033</td>
</tr>
<tr>
<td>ln(Income)</td>
<td>-0.016</td>
<td>-0.016</td>
<td>-0.016 (.)</td>
</tr>
<tr>
<td>Health</td>
<td>0.026</td>
<td>0.026</td>
<td>0.026</td>
</tr>
<tr>
<td>HoH</td>
<td>-0.046</td>
<td>-0.046</td>
<td>-0.046</td>
</tr>
<tr>
<td>Alcohol</td>
<td>-0.033</td>
<td>-0.036</td>
<td>-0.034</td>
</tr>
<tr>
<td>Tobacco</td>
<td>-0.104</td>
<td>-0.100</td>
<td>-0.103</td>
</tr>
<tr>
<td>Northeast</td>
<td>0.034</td>
<td>0.032</td>
<td>0.033</td>
</tr>
<tr>
<td>Valid</td>
<td>0.846</td>
<td>0.846</td>
<td>0.846***</td>
</tr>
<tr>
<td>Understood</td>
<td>-0.010</td>
<td>-0.011</td>
<td>-0.010</td>
</tr>
<tr>
<td>Prior</td>
<td>0.021</td>
<td>0.018</td>
<td>0.020</td>
</tr>
<tr>
<td>Order</td>
<td>1.200</td>
<td>1.200</td>
<td>1.200***</td>
</tr>
<tr>
<td>AIC Weight</td>
<td>0.718</td>
<td>0.281</td>
<td>0.999</td>
</tr>
<tr>
<td>P(Difference)</td>
<td></td>
<td></td>
<td>0.050</td>
</tr>
</tbody>
</table>

Results of the 2 dominant models and the averaged model (weighted for national representativeness). A positive coefficient on any demographic variable or the intercept means respondents were more likely to favor cure over bankruptcy.

**BANK** = 1 − probability of bankruptcy. **CURE** = probability of cure. **Married** = married or living with partner. **NumKids** = number of children. **Inc** = income. **HoH** = respondent identifies as the head of household. **Alcohol** = less than 1 drink per month. **Tobacco** = any tobacco use. **HoH** = identifies as the head of household. **White** = identifies as white, non-Hispanic. **Northeast** = location in the Northeastern United States. **Health** = “How would you rate your current state of health? (0–10)” **Understood** = “How well do you feel you understood this survey? (0–10)” For an explanation of **Valid** and **Order**, see the text.

**AIC Weight**: represents the weight applied to the results when calculating the overall model. **P(Difference)** reflects whether the coefficients on ln(BANK) and ln(CURE) are statistically significantly different from each other. Numbers higher than 0.05 indicate that neither value is statistically significantly higher than the other, and that, therefore, the null hypothesis that individuals value financial risk protection and cure equivalently cannot be rejected.

*** = significant at < 0.001, ** = significant at < 0.01, * = significant at < 0.05, (.) = significant at < 0.10  

$^a$Coefficients in the weighted model are corrected to a total weight of 1.00
FIGURE 3.1: Population indifference curve, controlling for demographic characteristics.

The x-axis represents the probability of cure, and the y-axis represents the probability of remaining financially solvent. The shallower the indifference curve, the more society preferences financial risk protection over cure. \( \text{BANK} = 1 - \text{probability of bankruptcy} \), \( \text{CURE} = \text{probability of cure} \). \( U = \text{utility} \). \( p \) for difference between cure and bankruptcy = 0.050

With increasing income, individuals trend toward being more likely to choose the alternative that provides a lower risk of bankruptcy at the expense of a lower chance of cure (\( p = 0.098 \)). Individuals who answered the validation questions correctly and those who ordered outcomes in the most common ordering were both more likely to choose
the option that provided a higher chance of cure \( (p < 0.001 \text{ in both cases}) \). No other sociodemographic variable approached significance.

### 3.3.3 Subgroup and Sensitivity Analysis

Table 3.6 and Figure 3.2 compare the effects of removing population weighting on the results of the averaged model. Without population weighting, financial risk protection is still preferred, but the difference is smaller and non-significant.

![Population weights](image)

**FIGURE 3.2:** The effect of population weighting, controlling for demographic indicators. Weighting for national representativeness flattens the indifference curve slightly. \( p \) for difference = 0.05 (weighted), and 0.142 (unweighted).
<table>
<thead>
<tr>
<th>Variable</th>
<th>With population weights</th>
<th>Population weights removed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-0.097</td>
<td>-0.661*</td>
</tr>
<tr>
<td>ln(BANK)</td>
<td>0.633***</td>
<td>0.785***</td>
</tr>
<tr>
<td>ln(CURE)</td>
<td>0.507***</td>
<td>0.712***</td>
</tr>
<tr>
<td>Age</td>
<td>-0.003</td>
<td>-0.001</td>
</tr>
<tr>
<td>Female</td>
<td>0.037</td>
<td>0.083</td>
</tr>
<tr>
<td>White</td>
<td>0.010</td>
<td>-0.005</td>
</tr>
<tr>
<td>Urban</td>
<td>0.105</td>
<td>0.108</td>
</tr>
<tr>
<td>Married</td>
<td>-0.111</td>
<td>-0.087</td>
</tr>
<tr>
<td>NumKids</td>
<td>-0.033</td>
<td>-0.040(.)</td>
</tr>
<tr>
<td>ln(Income)</td>
<td>-0.016(.)</td>
<td>-0.011</td>
</tr>
<tr>
<td>Health</td>
<td>0.026</td>
<td>0.027</td>
</tr>
<tr>
<td>HoH</td>
<td>-0.046</td>
<td>-0.065</td>
</tr>
<tr>
<td>Alcohol</td>
<td>-0.034</td>
<td>0.079</td>
</tr>
<tr>
<td>Tobacco</td>
<td>-0.103</td>
<td>0.018</td>
</tr>
<tr>
<td>Northeast</td>
<td>0.033</td>
<td>-0.006</td>
</tr>
<tr>
<td>Valid</td>
<td>0.846***</td>
<td>0.789***</td>
</tr>
<tr>
<td>Understood</td>
<td>-0.010</td>
<td>0.015</td>
</tr>
<tr>
<td>Prior</td>
<td>0.020</td>
<td>0.142(.)</td>
</tr>
<tr>
<td>Order</td>
<td>1.200***</td>
<td>1.450***</td>
</tr>
<tr>
<td>P(Difference)</td>
<td>0.050</td>
<td>0.142</td>
</tr>
</tbody>
</table>

A positive coefficient on any demographic variable or on the intercept means the respondents were more likely to favor cure over bankruptcy, and vice versa for a negative coefficient. All model coefficients were corrected to an AIC weight of 1.0. For an explanation of the row headings, see Table 3.5.

*** = significant at < 0.001, ** = significant at < 0.01, * = significant at < 0.05, (.) = significant at < 0.10
Table 3.7 summarizes the results of subgroup analyses, using the population-weighted sample. In all subgroups but one (see below), the preference for improved financial risk protection over an improved probability of cure remains intact.

**TABLE 3.7: Subgroup analyses**

<table>
<thead>
<tr>
<th></th>
<th>Age 65+</th>
<th>Age &lt;65</th>
<th>Male</th>
<th>Female</th>
<th>Employed outside the home</th>
<th>Not employed outside the home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-0.274</td>
<td>0.053</td>
<td>-0.226</td>
<td>-0.277</td>
<td>0.239</td>
<td>-0.212</td>
</tr>
<tr>
<td>ln(BANK)</td>
<td>0.641***</td>
<td>0.628***</td>
<td>0.632***</td>
<td>0.629***</td>
<td>0.649***</td>
<td>0.632***</td>
</tr>
<tr>
<td>ln(CURE)</td>
<td>0.590***</td>
<td>0.442***</td>
<td>0.491***</td>
<td>0.523***</td>
<td>0.533***</td>
<td>0.500***</td>
</tr>
<tr>
<td>Age</td>
<td>-0.002</td>
<td>-0.006</td>
<td>—</td>
<td>—</td>
<td>-0.002</td>
<td>-0.006</td>
</tr>
<tr>
<td>Female</td>
<td>-0.119</td>
<td>0.176</td>
<td>—</td>
<td>—</td>
<td>0.175</td>
<td>0.057</td>
</tr>
<tr>
<td>White</td>
<td>-0.009</td>
<td>0.021</td>
<td>—</td>
<td>—</td>
<td>-0.014</td>
<td>0.164</td>
</tr>
<tr>
<td>Urban</td>
<td>-0.017</td>
<td>0.208</td>
<td>—</td>
<td>—</td>
<td>0.117</td>
<td>0.062</td>
</tr>
<tr>
<td>Married</td>
<td>-0.168</td>
<td>-0.095</td>
<td>—</td>
<td>—</td>
<td>-0.025</td>
<td>-0.199</td>
</tr>
<tr>
<td>NumKids</td>
<td>-0.040</td>
<td>-0.035</td>
<td>—</td>
<td>—</td>
<td>-0.023</td>
<td>-0.039</td>
</tr>
<tr>
<td>ln(Income)</td>
<td>-0.019</td>
<td>-0.011</td>
<td>—</td>
<td>—</td>
<td>-0.015</td>
<td>-0.013</td>
</tr>
<tr>
<td>Health</td>
<td>0.029</td>
<td>0.021</td>
<td>—</td>
<td>—</td>
<td>0.036</td>
<td>0.020</td>
</tr>
<tr>
<td>HoH</td>
<td>-0.004</td>
<td>-0.028</td>
<td>—</td>
<td>—</td>
<td>0.166</td>
<td>-0.221</td>
</tr>
<tr>
<td>Alcohol</td>
<td>-0.068</td>
<td>0.003</td>
<td>—</td>
<td>—</td>
<td>-0.054</td>
<td>0.033</td>
</tr>
<tr>
<td>Tobacco</td>
<td>-0.205</td>
<td>-0.005</td>
<td>—</td>
<td>—</td>
<td>-0.293(. )</td>
<td>0.023</td>
</tr>
<tr>
<td>Northeast</td>
<td>0.100</td>
<td>-0.017</td>
<td>—</td>
<td>—</td>
<td>-0.073</td>
<td>0.116</td>
</tr>
<tr>
<td>Valid</td>
<td>0.993***</td>
<td>0.756***</td>
<td>0.824***</td>
<td>0.887***</td>
<td>0.686***</td>
<td>1.030***</td>
</tr>
<tr>
<td>Understood</td>
<td>0.000</td>
<td>-0.019</td>
<td>-0.010</td>
<td>-0.011</td>
<td>-0.062(. )</td>
<td>0.026</td>
</tr>
<tr>
<td>Prior</td>
<td>0.205</td>
<td>-0.164</td>
<td>—</td>
<td>—</td>
<td>-0.194</td>
<td>0.173</td>
</tr>
<tr>
<td>Order</td>
<td>1.250***</td>
<td>1.150***</td>
<td>1.150***</td>
<td>1.240***</td>
<td>1.113***</td>
<td>1.280***</td>
</tr>
<tr>
<td>P(Difference)</td>
<td>0.592</td>
<td>0.038</td>
<td>0.131</td>
<td>0.227</td>
<td>0.240</td>
<td>0.128</td>
</tr>
<tr>
<td>AIC Weight</td>
<td>0.974</td>
<td>0.950</td>
<td>1.000</td>
<td>1.000</td>
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Table 3.7 continues on the following page
Table 3.7, continued

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<td>ln(BANK)</td>
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<td>0.630***</td>
<td>0.834***</td>
<td>0.633***</td>
<td>0.594***</td>
<td>0.633***</td>
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<tr>
<td>ln(CURE)</td>
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<td>0.703***</td>
<td>0.845***</td>
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</table>

Average models for each subgroup, weighted for national representativeness, are presented, as well as the number of models that form the 95% confidence set. All model coefficients were corrected to an AIC weight of 1.0. Variable names follow Table 3.5.

*** = significant at < 0.001, ** = significant at < 0.01, * = significant at < 0.05, (.) = significant at < 0.10

In respondents who were under 65 (Figure 3.3), financial risk protection was much more important than cure, a difference that was statistically significant (\(p = 0.038\)). In those older than 65, cure increased in importance, but did not overtake financial risk.
protection. The difference was not statistically significant, and the null hypothesis—that both were equally important in older participants—could not be rejected.

There was little qualitative or quantitative difference in the indifference curves of men vs. women (Figure 3·4) or between those employed outside the home compared with those who were not (Figure 3·5). Children had a strong effect on the MRS (Figure 3·6): financial risk protection was most strongly preferred in those with 1 – 2 children ($p$ for difference = 0·022). In those with more than two children, the MRS displayed a preference for cure, but this was not statistically significant. Those with no children displayed an indifference curve that fell between the other two groups. Comparing individuals with lower self-reported health to those with higher self-reported health did not change the relationship between financial risk protection and cure (not shown).
FIGURE 3.3: The effect of age, controlling for other demographic indicators. Those under 65 are more likely to be concerned with financial risk protection over cure \((p = 0.039)\) than those aged 65 and older.
FIGURE 3.4: The effect of gender, controlling for other demographic indicators. No significant difference is seen in the indifference curves of men vs. women.
FIGURE 3.5: The effect of employment outside the home, controlling for other demographic indicators.

No significant difference is seen in the indifference curves of those employed outside the home compared vs. those who are not.
FIGURE 3.6: The effect of children, controlling for other demographic indicators.

Those with 1–2 children display a marginal rate of substitution that preferences financial risk protection most strongly (p for difference = 0.02). Those with >2 children are most concerned with cure, with childless individuals falling in between the other two groups.

To test the effects of model specification itself on the results, two sensitivity analyses were performed. Because it is possible that the MRS and the ordering question measure the same thing, the latter was omitted from the estimation equation in the first sensitivity analysis. This did not change the significant preference for financial risk protection (p for difference = 0.045, Figure 3.7). On the other hand, excluding the individuals who picked the dominated alternative in validation questions brought the coefficients on cure and financial risk protection into approximate equality (p for difference= 0.65, Figure 3.8). In
both of these sensitivity analyses, health became a significant predictor of response—the healthier a respondent was, the more likely he or she was to choose the option that provided the higher probability of cure.

**FIGURE 3-7:** Including or excluding the ordering question within the model specification has no real effect on the results. Both groups’ findings are statistically significant.
FIGURE 3.8: The effect of including only individuals who picked the dominant alternatives on validation questions. These individuals exhibit a slightly higher preference for cure over financial risk protection, but this difference is not statistically significant ($p = 0.65$), whereas the full sample has a statistically significant preference for financial risk protection.

3.4 DISCUSSION
That the American healthcare system is expensive is well known [208]. Discussing the costs of care is often anathema, however, because its implication of rationed care goes against a respect for health [209, 210]. As Hall as stated, “When we are ill, we desperately want our doctors to do everything within their power to heal us, regardless of the costs involved” [211]. This cure-at-all-costs presupposition has led to thorny ethical debates [211] but has rarely been tested [210].
The results of this study suggest that the presupposition itself may be wrong. In fact, Americans appear on the whole more concerned with financial risk protection than with cure and have strong preferences for remaining financially solvent, even when cure is at stake. These results are statistically significant and robust to sensitivity analyses.

This deserves some explanation. The indifference curves given in the figures represent curves of equivalent preference. That is, the utility of any point on a curve is equivalent to that of any other point on the same curve, and curves toward the upper right are preferred to curves to the lower left. At the steeper portions of any one curve, an individual is willing to trade a lot of financial solvency for a small increase in cure, and vice versa on the flatter portions of the curve. However, the shape of the curves themselves gives information on the global tradeoff: the more vertical the curves are overall, the more a cure-at-all-costs presupposition would hold.

Results in this survey tend in the opposite direction. They indicate that an individual currently facing a 50% chance of cure and a 50% chance of bankruptcy would only be willing to trade a 4% increase in the risk of bankruptcy to gain a 5% improvement in the chance of cure.

Although the direction of preferences was robust to sensitivity analyses, the statistical significance was sensitive to whether the sample was weighted to national
representativeness and to which subgroups were analyzed. Importantly, however, under no weighting scheme and in no subgroup was there a statistically significant preference for incremental health protection over financial risk protection.

Americans under the age of 65 strongly preferred financial risk protection; for older Americans, this preference persisted but was smaller and not statistically significant. Although it is not completely clear whether this preference change is due simply to increasing age, decreasing health, or eligibility for Medicaid, it seems likely that the latter plays a role: in no model was age a significant predictor of choice, and the median self-reported health for both groups of individuals was 8.0.

No difference was seen between men and women and between those employed outside the home and those who are not. Having children had a differential impact on the indifference curve, as can be seen in Figure 3.6.

Notably, only two-thirds of respondents ranked the four possible outcomes of a hypothetical choice in what might be expected if health was strictly more important than financial solvency. 17% of respondents preferred death without bankruptcy to being cured but bankrupt, and 6% of respondents preferred death with bankruptcy to death without bankruptcy. The latter implies that, for some, bequest is of little importance.
As with any survey, this study has its limitations. The behavioral model underpinning these responses cannot be determined. Increasing income in this sample trends toward a stronger preference to sacrifice health to gain financial risk protection. What drives this is not known: It is possible, for example, that the experience of the rich is one of relatively good healthcare, so a treatment with a 10% cure rate is not read the same way as it would be by someone below the national poverty line. Similarly, a supposed 90% risk of bankruptcy may be an unimaginable to individuals who are largely well insured. Although the survey did not specifically ask about the insurance status of these patients, employment outside the home was not associated with any additional explanatory power in any model (see Figure 3·5).

The preference for financial risk protection over improved chances of cure is likely to be country- and context-specific. This study is of the general American public, but evidence exists that individuals with lethal diseases are more willing than the general public to accept medically toxic treatments if they offer even minimal benefit [187, 188]. Whether individuals with lethal diseases would also be willing to accept financially toxic interventions is a matter for future research. In addition, individuals identifying as white, non-Hispanic and those with a bachelor’s degree or higher are over-represented in completed surveys. Although population weighting did not impact the findings, it is impossible to know how much residual confounding occurs as a result of this representation.
Despite these limitations, the strengths of this chapter are what it can show. By performing a nationally-representative survey, these results are quite generalizable, and give an indication of the national willingness to trade an increased risk of bankruptcy for an increased chance of cure. This can give policymakers useful information for the development of further health policy, while the subgroup analyses may allow these policies to be tailored to various segments of the population. Finally, and this chapter presents methodology that can be modified and applied to global settings.

Getting medical care in the United States can be risky. Although a lot of emphasis has been placed on the risks of iatrogenic injury and medical error [212], patients face a risk to more than their health. Arguably, the risk of financial ruin is an equally far-reaching “complication” of medical care: a declaration of bankruptcy is associated with the loss of assets, potentially including non-primary homes and inheritances, as well as the destruction of an individual’s credit rating for 7 – 10 years.

Beginning with the Progressives in the 1910s, continuing through the establishment of Medicare and Medicaid, and culminating with the Affordable Care Act, the national conversation regarding health provision in the US has focused on increasing insurance coverage for patients seeking care. Although insurance is often believed to be protective, the majority of individuals who suffer medical bankruptcy in the US had insurance at the time of their catastrophic event [7].
The results of this survey highlight the fact that Americans may care more about financial risk protection than has previously been assumed. Providing financial risk protection that supersedes that provided by insurance may be necessary in the design of a rational health system.

3.5 CONCLUSION
The American population appears to value financial risk protection in health more strongly than may previously have been thought; a cure-at-all-costs mentality may not be present. These findings bring the financial burden of healthcare access in the US to the fore and must be kept in mind as health policy interventions are considered.
ABOUT THIS CONSENT FORM

Please read this form carefully. This form provides important information about participating in research. You have the right to take your time in making decisions about participating in this research. You may discuss your decision with your family, your friends and/or your doctor. If you have any questions about the research or any portion of this form, please ask us.

PARTICIPATION IS VOLUNTARY

You are invited to take part in this research because you are an adult over the age of 18. It is your choice whether or not to participate. If you choose to participate, you may change your mind and leave the study at any time. Refusal to participate or stopping your participation will involve no penalty or loss of benefits to which you are otherwise entitled.

WHAT YOU SHOULD KNOW ABOUT A RESEARCH STUDY

• A research study is something you volunteer for.

• Whether or not you take part is up to you.
• You can choose not to take part in the research study.
• You can agree to take part now and later change your mind.
• Whatever you decide, it will not be held against you.
• Feel free to ask all the questions you want before you decide.

WHAT IS THE PURPOSE OF THIS RESEARCH?
The purpose of this research is to determine how individuals assess the risk of bankruptcy and/or poverty when seeking medical care.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?
About 2,500 people will take part in this research.

HOW LONG WILL I TAKE PART IN THIS RESEARCH?
We expect the research to last only 5 minutes.

WHAT CAN I EXPECT IF I TAKE PART IN THIS RESEARCH?
As a participant, you will be expected to complete a computer-based survey. The survey responses will be anonymous and will not be linked to you in any way.

WHAT ARE THE RISKS AND POSSIBLE DISCOMFORTS?
No study is without risk. This study, however, has minimal risk to you as a participant.
There is always a risk of a breach of privacy, although we will minimize this risk by
making all responses anonymous. Because this study asks about bankruptcy and impoverishment, there is a small chance of psychological discomfort when answering these questions.

ARE THERE ANY BENEFITS FROM BEING IN THIS RESEARCH STUDY?

There are no direct benefits to you of taking part in this research. While we cannot promise benefits to society as a whole, we hope that the findings from this research will help inform patient-centered policies for care.

WHAT ARE MY ALTERNATIVES TO PARTICIPATING IN THIS RESEARCH?

The alternative to participating in this research is not to participate.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS RESEARCH?

No financial compensation will be provided for your participation in this study.

WHAT WILL I HAVE TO PAY FOR IF I PARTICIPATE IN THIS RESEARCH?

It will not cost you anything to participate in this research.

WHAT HAPPENS IF I AM INJURED AS A RESULT OF PARTICIPATING IN THIS RESEARCH STUDY?

If physical injury resulting from participation in this research should occur, although Harvard’s policy is not to provide compensation, medical treatment will be available from
your local provider, including first aid, emergency treatment and follow-up care as
needed, and your insurance carrier may be billed for the cost of such treatment. In
recommending such medical treatment, or providing it, the persons conducting this
research project are not admitting that your injury was their fault.

CAN MY TAKING PART IN THE RESEARCH END EARLY?
You may decide not to continue in the research at any time without it being held against
you. The person in charge of the research can remove you from the research at any time
without your approval for any reason.

IF I TAKE PART IN THIS RESEARCH, HOW WILL MY PRIVACY BE
PROTECTED? WHAT HAPPENS TO THE INFORMATION YOU COLLECT?
No identifying information will be collected. Data will be published only in aggregate,
and will be completely anonymous. Data collected, including your identifiable
information, may be seen by the Harvard Institutional Review Board (IRB) that oversees
the research. We may also share your information related to this study with other parties
including thesis committees and funding agencies, specifically the National Institutes of
Health.
IF I HAVE ANY QUESTIONS, CONCERNS, OR COMPLAINTS ABOUT THIS RESEARCH, WHOM CAN I TALK TO?

The Principal Investigator of this study: Mark G. Shime, MD MPH FACS. He can be reached by email on shrime@mail.harvard.edu or by phone (Fridays, 8am-5:30pm)

617·573·3431

• If you have questions, concerns, or complaints,

• If you would like to talk to the research team,

• If you think the research has hurt you, or

• If you wish to withdraw from the study.

This research has been reviewed by a Harvard Longwood Medical Area Institutional Review Board (HMS/HSDM or HSPH). If you wish to speak with someone from the IRB, please contact the Office of Human Research Administration (OHRA) at 617·432·2157 (or toll-free at 1·866·606·0573) or 90 Smith Street, Boston, Massachusetts 02120 for any of the following:

• If your questions, concerns, or complaints are not being answered by the research team,

• If you cannot reach the research team,

• If you want to talk to someone besides the research team,

• If you have questions about your rights as a research participant, or

• If you want to get information or provide input about this research.
STATEMENT OF CONSENT

I have read the information in this consent form including risks and possible benefits. All my questions about the research have been answered to my satisfaction. I understand that I am free to withdraw at any time without penalty or loss of benefits to which I am otherwise entitled.

1. I consent to participate in this study

2. I do NOT consent to participate in this study

[IF CONSENT=2 OR REFUSED; TERMINATE][PROMPT]
What we are studying

In the US, 50-70% of all bankruptcy is due to medical bills. This study considers the interplay between seeking medical care and running the risk of going bankrupt to pay for medical bills.

How it works

In this study, we ask you to imagine that you are suffering from a disease that will kill you without treatment. You will answer a series of 7-12 questions that ask you to pick between two hypothetical treatments for this disease. Each treatment offers a chance of completely curing you and a chance of forcing you into bankruptcy. The treatments are otherwise identical in every other way.

What does "bankruptcy" mean?

For the purposes of this study, consider that bankruptcy means you will go into debt that you will be forced to pay back. You might lose your home and will lose most of your money, bank accounts, and other assets. Your credit rating will show that you have gone into bankruptcy for 7-10 years. If your debt is not paid off and you die, your children’s inheritance, if you have them, may be used to pay the debt.

What does "complete cure" mean?

For the purposes of this study, consider that complete cure means that you will be cured of this episode of the disease. You may or may not have the disease come back in the
future, but you cannot know that at this point.

There are, then, four possible outcomes of this choice:

- Cured and not bankrupt
- Cured and bankrupt
- Dead and not bankrupt
- Dead and bankrupt

What does it mean if a treatment has a 90% chance of cure and a 50% chance of bankruptcy?

This means that if 100 people chose that treatment, 90 of them would be cured, and 50 of them would go bankrupt, on average. Each question will give you this information

numerically and graphically, as below:
Click Next to begin the survey. And remember, there are no right answers.
Validation

[RANKING QUESTION] [NUMBER BOX; RANGE 1-4] [RANDOMIZE AND RECORD THE ORDER]

1. Please rank the four possible outcomes of a treatment choice, in order of what you would prefer most to what you would prefer least. (Where 1 = most preferred, 4 = least preferred)

1. Cured and Not Bankrupt
2. Cured and Bankrupt
3. Dead and Not Bankrupt
4. Dead and Bankrupt
2. Imagine you have a condition that cannot be cured without treatment. You are offered the two treatments below.

Which of these 2 treatments do you prefer?

1. TREATMENT A
2. TREATMENT B
[DISPLAY IF Q2 = 1 (TREATMENT A)]

It appears you have chosen the option with the \textit{lower} chance of cure and the \textit{higher} risk of bankruptcy. Although there are no right answers to these questions, we wanted to point that out.

\begin{table}[h]
\centering
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\hline
\textbf{TREATMENT A} & \textbf{TREATMENT B} \\
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\hline
50\% chance of bankruptcy & 25\% chance of bankruptcy \\
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\includegraphics[width=0.4\textwidth]{cure_a} & \includegraphics[width=0.4\textwidth]{cure_b} \\
\hline
50\% chance of cure & 75\% chance of cure \\
\hline
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This is the only time you will see this page.
Imagine you have a condition that cannot be cured without treatment. You are offered the two treatments below.

**TREATMENT A**

10% chance of bankruptcy

**TREATMENT B**

25% chance of bankruptcy

90% chance of cure

75% chance of cure

Which of these 2 treatments do you prefer?

1. TREATMENT A
2. TREATMENT B
[DISPLAY IF Q3 = 2 (TREATMENT B) AND THE RESPONDENT DID NOT SEE THIS PAGE PREVIOUSLY AFTER ANSWERING Q2]

It appears you have chosen the option with the lower chance of cure and the higher risk of bankruptcy. Although there are no right answers to these questions, we wanted to point that out.

TREATMENT A

10% chance of bankruptcy

TREATMENT B

25% chance of bankruptcy

90% chance of cure

75% chance of cure

This is the only time you will see this page.
**RANDOMIZATION**

Each respondent gets **two** blocks of five questions, formatted as above.

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</tr>
<tr>
<td>Choice 2</td>
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</tr>
<tr>
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<td>Choice 3</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td>Choice 4</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Choice 5</td>
<td>10</td>
<td>75</td>
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</table>

<table>
<thead>
<tr>
<th>Block 5</th>
<th>Treatment A</th>
<th>Treatment B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Chance of bankruptcy</td>
<td>Chance of cure</td>
</tr>
<tr>
<td>Choice 1</td>
<td>25</td>
<td>75</td>
</tr>
<tr>
<td>Choice 2</td>
<td>90</td>
<td>50</td>
</tr>
<tr>
<td>Choice 3</td>
<td>50</td>
<td>90</td>
</tr>
<tr>
<td>Choice 4</td>
<td>50</td>
<td>25</td>
</tr>
<tr>
<td>Choice 5</td>
<td>75</td>
<td>90</td>
</tr>
</tbody>
</table>
**DEMOGRAPHICS**

D1. How would you rate your current state of health?

<table>
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<tr>
<th>Perfect health</th>
<th>10</th>
<th>9</th>
<th>8</th>
<th>7</th>
<th>6</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
</table>

D1A. Have you, or has anyone in your immediate family, currently or ever been diagnosed with a serious disease like cancer or end-stage kidney disease?

- Yes, I currently have such a disease.................................................................1
- Yes, I used to have such a disease................................................................. 2
- Yes, one of my family members has such a disease ........................................... 3
- Yes, one of my family members used to have such a disease ............................ 4
- No ....................................................................................................................... 5

[IF D1A = 3 OR 4]

D1B. Do you or did you serve as the **primary** caretaker for your family member with the serious disease?

- Yes.......................................................................................................................1
- No .................................................................................................................... 2
D8. How would you characterize where you live?

1. National capital
2. Large urban (> 5 million people)
3. Urban (1 million - 5 million people)
4. Suburban
5. Rural
6. Other ___________________

D9. How much tobacco do you smoke?

1. I don't smoke
2. Less than 1/2 a pack per day
3. 1/2 to 1 pack per day
4. 1 to 2 packs per day
5. More than 2 packs per day

D10. How many alcoholic drinks do you drink?

1. Never
2. Less than 1 drink per MONTH
3. 1-4 drinks per MONTH
4. 2-4 drinks per WEEK
5. 4-7 drinks per WEEK
6. More than 7 drinks per WEEK
D12. Please indicate your current household income in U.S. dollars per year.

1. Under $10,000
2. $10,000 - $19,999
3. $20,000 - $29,999
4. $30,000 - $39,999
5. $40,000 - $49,999
6. $50,000 - $74,999
7. $75,000 - $99,999
8. $100,000 - $149,999
9. $150,000 - $199,999
10. $200,000 - $249,999
11. $250,000 - $300,000
12. More than $300,000
13. Prefer not to say

D13. Do you work outside the home?

1. Yes
2. No
D14A. How many children do you have (whether or not they currently live with you)?

__________ [RANGE 0-20]

D15. How well do you feel like you understood this survey?

<table>
<thead>
<tr>
<th>I understood it perfectly.</th>
<th>10</th>
<th>9</th>
<th>8</th>
<th>7</th>
<th>6</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>I did not understand it at all.</td>
<td></td>
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</tbody>
</table>

[OTHER DEMOGRAPHIC VARIABLES HAVE BEEN PREVIOUSLY COLLECTED BY THE SURVEY COMPANY]
WORKS CITED


124. Bolkan, H., et al., *More than 90% of surgical need is unmet in Sierra Leone: Results from a 2013 countrywide survey* 2014, Norwegian University of Science and Technology.


170. McFadden, D., Modeling the choice of residential location, C.F.f.R.i.E. Yale University, Editor. 1977: Yale University.


