Introduction: the quest for coverage and legitimacy

In 2003, the Mexican government took a step toward greater parity in its health system. The stubbornly fragmented health sector remains fragmented, but a new health insurance program to fund basic preventive and curative services was created to cover nearly half of the population which had previously been without effective insurance coverage. The “Seguro Popular,” (SP) the medical care component of the System for Social Protection in Health, consisted of two insurance packages. The first, currently known as CAUSES (Catálogo Universal de Servicios Esenciales de Salud), covers services with relatively low costs and high incidence. The second is the Fund for Protection from Catastrophic Expenses (Fondo de Protección contra Gastos Catastróficos, FPGC), which covers a small list of diseases with lower incidence but high costs. As of mid-2006, SP covered 249 standard interventions through CAUSES and 6 through FPGC.

As with any insurance program, the creation of both CAUSES and FPGC have required policymakers to make tough choices about what services should be covered and what should be left out. These choices have been affected by political, economic, clinical and ethical considerations. This case study focuses on the initial decisions surrounding the coverage of the FPGC and the search for a more rational and fairer decision-making process. The creation of the package for CAUSES was largely finished prior to the establishment of the program, and was based on folding a variety of older programs and packages into a single insurance scheme, with some important additions. The decisions about what the FPGC would cover, however, were left until after the SP was already up and running.

With limited resources, complex, multivariate decisions must be made by societies and their governments about which sick people should receive public support. Consider a real-life example from the Mexican case. One category of illness which has been considered for inclusion in the catastrophic fund comprises what are known as “lysosome storage diseases” (LSD). These are genetic ailments resulting from the lack of an important enzyme within that allows cells to metabolize molecules. In patients for whom the disease is activated early on, there is a high chance of dying in childhood if LSDs are untreated. The cost of treating LSDs for which treatment exists is about US$220,000 per year, per patient, which is prohibitively expensive for nearly all Mexicans. However, it is estimated that about 200 people in the entire country, representing about 2 persons per million, is affected by the disease group. The General Health Counsel estimates that fewer than 30 people with LSDs in Mexico are uninsured, and would be covered by the FPGC were LSD to be included.  

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1 A third package known as CASSCO (Catálogo de Servicios de Salud a la Comunidad) covers population based public health services delivered independent of insurance status. It currently includes 58 interventions.

2 Solicitud de Atención de Pacientes con Enfermedad Lisosomal en el Seguro Popular, Febrero 28 2006, 3.
Most people would agree that people with LSD should be covered if there were unlimited resources for the health sector. But how should LSD patient demands for treatment be weighed in comparison with the demands of patients with other diseases, such as breast cancer? Estimates produced by the Mexican Ministry of Health in 2003 estimate a far higher prevalence for breast cancer in Mexico, about 156 cases per million per year. This amounts to about 7800 new cases per year in the uninsured sector covered by FPGC. Breast cancer predominantly affects middle-aged women. The estimated cost of treating these patients per patient, per year, is less than one tenth the cost of treating LSDs, under US$20,000 per year.

Given limited resources, which of these diseases should receive coverage? This is an artificial simplification of the problem, because these diseases have to be compared with a wide range of other high cost diseases. In fact, the Mexican government has a working list of over 60 potential diseases for inclusion in the FPGC. But even in the simple pair-wise comparison presented here, a variety of difficult issues arise. Many people would feel that the prevalence of breast cancer should give it a higher priority than LSDs. On the other hand, the cost of breast cancer is far lower and is less catastrophic for many Mexicans than LSDs. LSDs may kill young people, while untreated breast cancer has a higher probability of leading to death, but affects middle-aged females. Inevitably, decisions like this one create winners and losers, and this in turn creates strong incentives for various actors to attempt to pressure policymakers to favor particular disease groups.

This case study looks at the origins of the FPGC and how it has evolved. The Ministry of Health has moved from a position of ad hoc decision-making to the search for a more rational, transparent and justifiable process of expanding FPGC coverage. The problem facing the FPGC is unique, with little to draw on by way of international experience: other systems that have procedures for evaluating new technologies are designed to make modest additions at the margin of their systems, whereas the benefit package of the FPGC has been created from scratch. At the same time, losers—those not covered by a particular decision—often know that Mexican workers insured through other schemes may well receive these benefits, shining a harsh spotlight on the decisions that are made. This paper explains how and why the original coverage decisions were made, and why the MOH has sought an alternative decision-making process.

One of the authors of the case study, Norman Daniels, has been intimately involved in changes to the process used by the Mexican government to make determinations of which diseases will be covered. Daniels has served as a consultant to the government in its search for a new process. This study analyzes the development of the FPGC prior to Daniels’s involvement, but also draws on the consultations between Daniels and government officials in order to illuminate the challenges of implementing a fair and ethical process for decision-making in the health sector.

The study is important because it highlights the political, intellectual and bureaucratic challenges of implementing ethical procedures in the context of public service delivery. Arguably, one obstacle to implementation has been the desire of powerful actors to retain control, or in some cases to take back control, over aspects of health coverage that they considered to be their prerogative. But disciplinary and bureaucratic blinders have been at least as important. Motivated by a desire for consistent, easily obtainable and quantifiable
outputs, technical “experts” from within the government also resisted the creation of a truly deliberative and open process of decision-making.

The history of the search for a “fair process” to make coverage decisions reflects the broader history of the way in which Seguro Popular was created and implemented. SP was conceived by a small group of experts within MOH, operating in a highly exclusive fashion. As the program moved from the pilot phase to the implementation phase, a more inclusionary approach was needed to achieve support from a far wider array of actors. This in turn led to a search for a more democratic and transparent approach to decision-making, which would allow new actors to buy in to program goals.

The paper proceeds as follows. In the next section, we describe in greater detail how the FPGC was designed and what it covers. We then explain why it looks the way it does. The fourth section of the paper explores the process of searching for a new decision-making process. At this point we provide a brief overview of Daniels and Sabin’s concept of “accountability for reasonableness” (A4R), drawing on materials presented to workshops with Mexican health officials in March and August 2006. We then look at how the current process is being implemented, and the obstacles it faces. Finally, we set our sights on the future and what is to be expected as Mexico transitions to a new president.

How it works

The FPGC is financed by reserving 8 percent of total revenues dedicated to Seguro Popular. Funds are disbursed from the FPGC to the providers on the basis of medical events, rather than on the basis of a capitation fee per family enrolled, which is the structure of the basic package. The fund is administered centrally by a body known as the Comité Técnico del Fideicomiso del Sistema de Protección Social en Salud, unlike the rest of the health system, which is administered at the state level. As a result, the FPGC constitutes a national risk pool for catastrophic illnesses, rather than a risk pool limited to the population of each state. The Comité Técnico del Fideicomiso is essentially responsible for allocating the available resources to cover treatment for approved diseases insofar as there is sufficient money in the Fund to do so.

Prior to the creation of the FPGC, however, the Consejo de Salubridad General (CSG), under the direction of Dra. Mercedes Juan, had made a list of 60 treatments which were potential candidates for coverage. These were in turn drawn from nine broad disease categories included in the law. The CSG is an autonomous arm of the Mexican government with a long history of independent decision-making. The CSG has historically played an important role in the prioritization of treatments for disease. It has always directed the creation of the government’s “Basic Tables,” the list of treatments which are clinically approved and should be made available to the population in all public facilities.

According to the CNPSS, the six diseases currently covered by the fund are: antiretrovirals (ARTs) for HIV, child acute lymphoblastic leukemia, cervical cancer, and three neonatal complications (respiratory insufficiency, neonatal sepsis, and premature newborn). In 2006, cataracts have also been added and additional child cancers are being integrated. As of the first semester of 2006, funds from the FPGC had only been used to provide ART for HIV, treatment for acute lymphoblastic leukemia, cervical cancer and some neonatal
complications. No funds had been dispersed, according to official records, for new cases of cataracts or other child cancers. By November of 2006, however, funds from the FPGC had been disbursed to cover some other child cancers and cataracts. Funds were slated to be disbursed to cover dialysis for kidney failure in 2007, a decision announced by former president Fox in mid-2006 which still is under discussion.

Surprisingly, in the past couple of years, funds from the FPGC have also gone to pay for two vaccines outside of the initial mandate of the FPGC: influenza in 2004, and pneumococcus in 2006. We will explore the reasons for this aberration below.

*Why does it work this way?*

This section attempts to answer the following questions. Where did the nine categories in the law originate? How were the first 60 interventions which fit into those categories generated by CSG? How did the additional interventions enter, and how were the final interventions, those which are currently covered, chosen? What actors were involved in these decisions, and was there opposition to the decisions which were ultimately taken?

**The nine categories.** The original nine categories in the law were chosen for both technical and political reasons. Technically, the categories were based on an analysis of cost-effectiveness, disability-adjusted life years, and overall cost. Politically, they responded to critics of SP who were dissatisfied with the program and wanted specific interventions to be covered. Many of these critics were from the General Health Council or had representation there, like the director of IMSS. The inclusion of HIV as its own category was based on a desire to build an alliance for the passage of SP with the active and visible HIV patient advocacy network. The nine categories came out of the process of negotiating the passage of the Seguro Popular legislation through the Mexican Congress. The Congress was particularly concerned about HIV, neonatal complications and women’s issues, given pressure from feminist NGOs which predated the debate over SP.

**The 60 candidate diseases.** These were chosen by the General Health Counsel (CSG), which convened nine groups of medical experts to deliberate over the diseases for each of the nine categories in 2004. Decisions were based on a combination of clinical and economic criteria, though there were serious data limitations. Specialists surveyed their own institutions for data on hospitalizations, with a bias toward the national institutions which are located in Mexico City. The most important consideration for determining which diseases would be covered was their prevalence. Cost considerations were also prominent. Some treatments that were extremely costly, like surgeries, were limited from the outset by Frenk’s team for budgetary reasons.

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3 Excluding HIV, in 2005, over half of the cases receiving funds from the FPGC were for cervical cancer treatment, and about a third were for neonatal intensive care. The rest of the funds went to leukemia. Interestingly, in 2004, nearly 75 percent of the cases were neonatal intensive care treatments. See CNPSS, *Informe de Resultados, Primer Semestre 2006*. HIV spending in 2006 accounted for most of the FPGC’s resources, about 65 percent. Interview with Hector Peña.

4 Interview with Hector Peña, CNPSS.

5 Interview with Hernandez Llamas; Interview with Miguel Angel Lezana.

6 Interview with Maria de las Nieves.

7 Interview with Dr. Rivera-Luna (INPediatría); Interview with Dr. Salinas (INPerinatología).
The additional four candidate interventions. At this stage, government officials were lobbied by various groups. Primarily as a result of this lobbying, four additional interventions have been added to the candidate list: lysosome storage disorders (LSDs), cataracts, hemophilia and meningitis. In this section, we review the circumstances surrounding the addition of these interventions to the candidate list.

Advocates for victims of lysosome storage disorders had lobbied the government since 1999 for coverage in both Social Security and the uninsured population. Meetings were held with Secretary Frenk and members of Congress during the first years of the Fox presidency. In 2003, the government increased coverage within Social Security. This satisfied some patient advocates, because most of those who needed the disease were either already covered by Social Security or could find a way to enter.

In February 2006, an anti-discrimination lawsuit, filed by other LSD patients and supported by Boston-based pharmaceutical company GENZYME, the maker of the treatment for LSD, was filed with the National Council for the Prevention of Discrimination (CONAPRED). The suit alleged that the failure to provide disease coverage to the uninsured was a discriminatory violation of the human rights of the sick. In response to this suit, the CSG decided to include LSD coverage in the candidate list.

The case of cataract surgery also involved pressure from non-governmental actors. In the event, the Gonzalo Rio Arronte Foundation wanted to donate about $50 million to the cause of increasing cataract surgeries to about 30,000 per year. The Foundation generally donates money only to the investment in equipment, so it wanted to partner with the MOH to provide the services. The Foundation’s health program is headed by Jesus Kumate, a politically well-connected former Secretary of Health. Kumate directly approached Secretary Frenk and asked him to put up a match of about $50 million to pay for the human resources and incidental costs of the surgeries. Frenk agreed but was unable to put up the money right away. The Foundation approved the grant, but ultimately waited nearly 3 years until MOH was able to match it.

There has also been patient pressure to include hemophilia. Hemophiliacs, represented by the Hemophilia Federation, are a well-organized and persistent interest group. The Hemophilia Federation requested coverage by the FPGC in April of 2005, and again in September of 2006. Between these two requests, at least one public functionary at MOH promised the group that the disease would receive coverage. In addition, a technical protocol was created, and the disease entered the list of candidates for inclusion. While the

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8 These diseases were added between August, 2005 and May, 2006. Cataracts were added on August 31, 2005; LSDs and hemophilia were added in March 2006, and meningitis was added in May 2006.
9 Interview with Manuel Casamayor, Asociación Gaucher.
11 Interview with Jose Angel Cordova Villalobos.
12 Interview with José Andres Santos Gonzalez.
13 Interview with Jose Angel Cordova Villalobos.
petition for inclusion of hemophilia in the FPGC appears to have been viewed favorably, it has not yet moved from the candidate list to the FPGC for lack of funding.\textsuperscript{14}

Finally, the inclusion of meningitis has responded to financial and political imperatives internal to MOH. Because the funds were available in the FPGC, but no funds had been made available in the rest of the prevention budget that supports CASSCO interventions, when the Secretary decided to pursue a vaccine for meningitis, he decided to petition the Comité Técnico del Fideicomiso for the money. There initial response was that they could not pay for meningitis vaccines unless the disease was on the CSG’s candidate list as a “catastrophic” disease. So meningitis was added to this list in order to expedite the purchase of the vaccine. This was a clear example of funding being diverted for purposes which could not be construed as within the original mandate of the FPGC.\textsuperscript{15}

**The initial four covered interventions.** The initial four diseases were chosen by Julio Frenk. No formal consultations with any actors, either within MOH or external to it, were taken. Two of the four had some basis in existing programs: HIV and neonatal complications. But the other two were completely discretionary, as was the decision to cover four diseases, as opposed to a larger set.

ART for HIV was selected for a variety of reasons. First, as noted above, the HIV lobby is very strong and was an important ally in the passage of the bill. In addition, anti-retroviral treatment (ARVs) for HIV was already being financed for the uninsured population through a separate program. Folding this program into FPGC did not require a lot of new resources.\textsuperscript{16}

Similarly, some aspects of the neonatal package were already being provided to the uninsured population through a separate program, Arranque Parejo en la Vida, which was created earlier in President Fox’s term to reduce maternal and infant mortality.\textsuperscript{17} Neonatal coverage is also good politics, as it tends to generate widespread support. Women’s groups had also been demanding such coverage for many years.

The case of leukemia was politicized by President Fox. President Fox visited Asociación Mexicana de Ayuda a Niños con Cáncer (AMANC) in 2002 and promised his support to the cause of providing resources for children with cancer. His wife also became involved with AMANC and made contacts at the state level for the organization. The decision to include children with cancer seems to have been driven largely by political symbolism and the president’s dedication to the issue.\textsuperscript{18}

Cervical cancer coverage was decided upon relatively early. One reason for its inclusion was that the health sector had a reasonably good track record at identifying cervical cancer, but was often unable to treat it. Covering treatment was a natural next step and logical candidate

\textsuperscript{14} Consejo de Salubridad General, “Nota Informativa: Solicitud de atención de pacientes con hemofilia en el Seguro Popular,” September 19, 2006.
\textsuperscript{15} Interview with Gabriel Sotelo.
\textsuperscript{16} Interview with Lezana.
\textsuperscript{17} Interview with Gabriel Sotelo.
\textsuperscript{18} Interview with Maria Alejandra, AMANC; Interview with Octavio Gómez-Dantés.
for inclusion. In addition, the symbolic politics of covering an important disease for women played a role.\(^{19}\) In the past, pressure by influential congresswomen had led to increases in the health budget for diseases which particularly affected women, but never as part of an overall MOH strategy; including cervical cancer was intended to institutionalize women’s pressure for health resources within MOH. In addition, MOH analysis from 2003 showed that cervical cancer was estimated to cost about half of breast cancer, which would have had similar symbolic value.

Within the health sector, there was some concern about how diseases were being selected. Even without any particular process, the decisions appeared to some as excessively arbitrary. For example, if the Secretary had chosen nine diseases to be covered, one from each of the nine categories, this would have seemed less arbitrary to some, if no more inclusive.\(^{20}\) And while a good case could be made for including the diseases which were chosen, it was not clear what the case for exclusion necessarily was. For example, treating leukemia and cervical cancer were certainly justifiable, in terms of the high incidence of these diseases, and the cost-effectiveness of treating them. But a similar case could be made for “chronic renal insufficiency,” which was not included. And while cervical cancer certainly deserved coverage, it appeared that the primary reason that prostate cancer did not also receive coverage was that interest groups representing women were more vocal than those representing men. This might make political sense, but it did not necessarily make clinical or ethical sense.

**The additional neonatal complications, cataracts and beyond.** With the addition of the last diseases to be covered up to now by the FPGC, tensions over the decision-making process were further magnified. The supplementary interventions included were cataract surgeries and further neonatal treatment. As we have seen, both of these decisions were driven in part by political pressure, and at least the former was driven by the intervention of a non-governmental organization with ties to influential policymakers.

The case of renal insufficiency, coverage for which is still under discussion, is telling. After the president, without warning, made a dramatic public announcement in April 2006 that it would be covered, it rose quickly to the top of the agenda. As the program was implemented in 2005 and 2006, the president and the broader political context began to impinge further upon the decision-making process. The president used SP as a signature accomplishment of his administration for electoral purposes, and continued to make public statements about coverage. In addition to the case of renal insufficiency, the president also made claims in 2005 about universal cancer coverage. These claims were not consistent with the coverage provided by SP at the time, but they served to increase public pressure to include more diseases.

Summing up this section on how the FPGC got to include the interventions it does, the lack of clear guidelines and the importance of politics and interest group pressure is striking. As the program got off the ground and the president publicized it further, various interest groups began to put pressure on MOH to provide coverage for particular diseases. This led to concern on the part of MOH and the CSG that the decision-making process was

\(^{19}\) Interview with Hernandez Llamas.

\(^{20}\) Interview with members of Consejo de Salubridad General.
descending into anarchy and that it would ultimately be overrun by lobbyists, while both clinical and economic criteria would be sidelined.

Undoubtedly, civil servants in both institutions also felt that they, and technical health experts more generally, had been excluded from the decision-making process, while particular civil servants and interest groups with better access to the Secretary were able to exercise more influence over policy choices. By this time, there was considerable resentment among some MOH employees with a clinical or public health background vis-à-vis the dominance of health economists in the reform process. For example, the CSG, which had always coordinated the creation of the formularies for pharmaceuticals and other medical supplies, had been excluded from the process of creating the basic package for SP. They were then given an explicit role in prioritization for the FPGC, but this role was being undermined by lobbyists and politicians pushing an agenda that mostly eschewed technical criteria. From the perspective of the Secretary and his close advisors, the convergence of the need to legitimate decisions both within the health sector, and to external actors and the wider citizenry, militated in favor of a search for a new process.

*The Search for a Process*

The idea of creating a formal process originated in meetings of Frenk with his team, meetings which have occurred every Monday since the beginning of the administration in 2001. Norman Daniels was brought in for a consultation in March of 2006. The CSG staff under Dra. Juan began to draft a manual which more fully described this process over the summer. Daniels returned to discuss the initial draft of the manual in August 2006, and a revised version of the manual was released in October.

In the meantime, the creation of working groups went forward. Four working groups were created: Ethics, Clinical, Economics, and Social Acceptability. The Economics group was led by Eduardo Gonzalez-Pier, who had a long history of working on cost-effectiveness and an able team. The Clinical group was under the direction of Dr. Alberto Lifschitz, who was appointed by Mercedes Juan. Lifschitz also has a long history of working on SP, having been involved in the initial selection of the 60 diseases by the CSG. Both of these groups were therefore led by high-level figures whose long association with the program prepared them to move ahead quickly with their charge.

The other two working groups have had distinctive trajectories. Their tasks were not well-defined and their leadership, unsurprisingly, was not as fully integrated into the SP team. After all, neither ethics nor “social acceptability” had been explicit aspects of the policymaking process before, whereas clinical and cost-effectiveness considerations had always been prominent. It appears that the creation of these groups was driven by Daniels’s consultation, and an attempt to embody the criteria written into the law.

The original head of the ethics group, Asunción Alvarez, was invited by Guillermo Soberón, Julio Frenk’s mentor and the Director of the National Bio-ethics Commission. (She was later replaced by a staff person, Gisela Morales, on the National Bioethics Commission.) The role of the ethics group was intensely debated. The group on Social Acceptability was convened
by Mercedes Juan, but as of the end of September, they had not yet met and had no clear vision of what they should do.

*Models of Process and Accountability for Reasonableness (A4R): Daniels’s Consultation*

Daniels’s consultation focused on the principles underlying “Accountability for Reasonableness” (A4R), a method for making decisions when resources are limited and people with reasonable claims to those resources cannot all be served, and where reasonable moral disagreement about priorities obtains (Daniels and Sabin 2002). A4R prescribes and justifies four conditions that a limit-setting procedure must meet for it to be legitimate, in the sense that its decisions should be accepted by those affected even if they disagree with them, and for its decisions to be *fair*.

The four conditions are:

1. **Publicity**: People who are denied care and the public as a whole should be able to know the rationale for the denial of coverage. People have a basic interest in knowing why decisions that fundamentally affect their well being were made, and without that knowledge they are less well equipped to pursue appeals of unfair or inappropriate decisions.

2. **Relevant Reasons**: Decisions should rest on reasons that *fair-minded* people can agree are relevant to the decision. Fair-minded people are those who seek mutually acceptable justifications for their decisions. By including a broad range of stakeholders in the decision-process, it is more likely that a full range of reasons will be canvassed and the results viewed as acceptable. People may still disagree with decisions, perhaps because different weights are given to relevant reasons, but at least losers will not think a decision was made for entirely irrelevant and wrong reasons. As a result, the range of disagreement may be lessened. The rationale that emerges is thus the result of a deliberative process that takes value disagreements seriously, but also seeks to be clear about the empirical evidence.

3. **Revisability**: Decisions must be open to revision in light of new evidence and arguments. In addition, decisions should be open to appeal by those who believe they are being unfairly treated in light of them.

4. **Enforcement**: There is either self- or external regulation of the procedure to ensure that the above conditions 1-3 are met.

Together these conditions hold decision-makers accountable for the reasonableness of their decisions. The strong publicity condition promotes wider social learning about priority or limit setting and establishes a kind of case law, spelling out reasons for specific decisions. These four conditions have been widely embraced in other settings. For example, the head of the National Institute for Clinical Excellence (NICE) in the UK cites accountability for reasonableness as an influence on the design of that process; the approach has been endorsed in the WHO Guidelines for Equity in scaling up antiretroviral treatments for HIV/AIDS, and a recent IOM report suggests that cost-effectiveness be viewed as an input to a fair deliberative process of this sort.

Daniels presented the conceptual framework for A4R to the Mexican government, but he did not describe in detail how the process should be operationalized in the case of FPGC. Mexican officials opted to incorporate aspects of the approach, but also pursued very different models initially as well. The first draft manual explaining how the prioritization
process would work was clearly driven by a desire to pursue an efficient approach that could be easily quantified and would avoid the untidiness of a truly deliberative process. Over time, however, policymakers shifted toward a more open and deliberative model.

Choosing a process

The first draft of the manual indicated that the four working groups would have co-equal status. Each working group would essentially use a unique set of indicators, related to the concerns of their particular discipline, to evaluate diseases. For example, the economics group would use standard cost-effectiveness measures. Ethics would use a single criterion: do covered medical treatments diverge from medical-ethical norms?21 Notably, this criterion was operationalized by asking of each individual disease if it could be treated in accord with the ethical principles of autonomy, welfare, avoiding harm, and “distributive justice.”22

Reasonably detailed instructions for converting these evaluations into a single, composite quantitative indicator were drawn up. Each of the four groups would generate a set of quantitative rankings, and then these rankings would be weighted (presumably equally) and put into an algorithm which would rank the diseases overall according to the findings of all four groups.

This model was unsatisfactory to the Ethics working group, and was criticized by Daniels. The primary concern from both quarters was that ethics should not and could not be treated just as another grouping that could be converted into a quantitative weight. Instead, the “fair process” required lively debate about different ethical principles with attempts to justify these principles and a search for consensus.

The role of the social acceptability (SA) working group was also unclear. What did social acceptability mean? A particularly important consideration was how open the SA group should be. Some officials wanted to keep tight control of this group, by inviting a limited set of actors to participate and give their input. Others felt that the process should be more open to anyone who wished to comment. Methodologically, the vision of the initial draft was questioned on similar grounds as that of ethics. It was initially proposed to send out a survey to gather information about social acceptability. Critics pointed out that, again, SA implied a deliberative process of weighting different considerations, and this would be very difficult to do with a survey.

In a revised manual produced in October, the methodology was altered. The Ethics group was put further downstream from clinical and economics, so that it would receive their work as inputs. Social Acceptability was given an overarching role, apparently receiving the inputs of all three of the other groups and determining whether it agreed with the recommendations of the Ethics group or not.

22 Ibid., 48.
Nevertheless, no further progress was made on clarifying the vision of how SA would function, and no meeting of the group had yet occurred.

Implementing the Process: Consultation and Working Group Meetings

In October, Daniels returned to Mexico to meet with both the Ethics and SA working groups for further consultation. During this visit, the SA working group met for the first time, and the Ethics group deliberated further what its role should be. A number of important concerns were raised across these formal meetings, as well as in informal interactions outside of them.

Ethics

The creation of an ethics group was foreseen in the regulations governing the CSG’s special committee created to analyze diseases for the FPGC. However, this document, passed in September 2005, refers not to ethics generally, but to the “professional, ethical norms” of medicine. The decision to bring in an external consultant to implement a process consistent with broader ethical considerations, as well as the choice of members of the Ethics Working Group (e.g., relatively few clinicians), suggests that these regulations have

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been in tension with the actual intention of some policymakers when including ethical norms in the fair process. The latest draft of the manual to guide the fair process continues to insist that the primary criterion which should be used by the Ethics group is professional norms. This is not, however, the understanding of the Ethics group, and they have made it clear that they believe their charge is to examine the big ethical issues in deciding who gets access to health services.

A meeting of the Ethics Working Group (EWG) was held on October 3, 2006. Norman Daniels was invited to meet with the group to discuss their progress and concerns. The group as a whole was uneasy about the way that diseases were being selected for consideration. They noted that they were receiving diseases one at a time from the Economics Working Group (EcWG), and these diseases often lacked clinical information. In the view of the EWG, the diseases they were receiving for evaluation were chosen arbitrarily, and some diseases were being eliminated before EWG was given a chance to consider them. As a result, it was not clear how to evaluate the diseases that were being sent. What was the correct comparison? Should each disease be evaluated in isolation? Was this possible? What was the relevant comparison group? The issue of how the diseases should be selected initially for evaluation by the four working groups was also discussed, and the possibility that the EWG might be the appropriate initiator of this process was considered.

The EWG grappled with a number of important issues in this meeting. They struggled with how conceptually to evaluate a large number of diseases across multiple dimensions according to a small number of just criteria. They also were anxious about their inability to agree on a general philosophical framework for decision-making, and were reluctant to accept the notion that “reasonableness” be the only general principle of discussion. And they expressed concern about the mechanics of their interactions with other groups. This concern related both to the inputs they received to make their recommendations, and the process by which their suggestions would be incorporated into the work of other groups or the overall process.

Social Acceptability

The nature of the social acceptability group was a matter of contention from the outset of the process. Interviews with key actors, as well as documents prepared by them, revealed some uncertainty about what social acceptability meant, and how it should be operationalized. Social acceptability, like ethics, was referred to in the 2005 regulations, but no explanation of the precise meaning of the phrase was given at that time.

To some, the concept referred to the need to get input from organized civil society. In this view, lobbyists and civil society groups had originally achieved opaque but important access to decision-makers. The purpose of the creation of a “fair process” was not to eliminate the influence of these groups, but to control and balance that influence alongside other criteria. The social acceptability group was to be a place where these interests could have some input in a more transparent way than in the past.

Others viewed social acceptability in a more diffuse way, as the general perception of society about the choices being made. This led several officials to propose the idea of using a survey instrument with a representative sample to extract a better sense of what decisions were
more “socially acceptable.” According to this perspective, the purpose of social acceptability was to reduce the influence of organized interests in civil society and get a more democratic picture of what average Mexicans wanted from their health system.

Yet another view of social acceptability was that it meant simply creating a closed space for public health officials to weigh the social benefits of disease coverage, away from the influence of either organized interests, or uninformed citizens. These social criteria included the effect of diseases on the families of the ill, and the burden of disease on particularly vulnerable populations, such as children under 5, or adults over 64 years old. The logic of this approach was that the decision-making process should not be dominated by lobbyists, but that society was not sufficiently informed or prepared to participate actively in decision-making. In order to balance the influence of doctors, economists and philosophers, however, there should be a group of public health officials who considered the social implications of the recommendations of these other groups. This vision of “social acceptability” is consistent with Mexico’s historically non-democratic tradition of policy-making. It also reflects a desire by technical experts to maintain technical control of the decision-making apparatus.

When Daniels arrived in Mexico in October, the membership of the Social Acceptability group was still not solidified. Informally, Daniels was told during his visit, but prior to meeting with the SAWG, that most of the people being considered for the group were public health “insiders,” rather than representatives of key groups like civil society, doctors, patient advocates, and so on. The idea of a survey had been considered as well, but both Daniels and members of the EWG were highly skeptical of the use of a survey to elicit opinions about complex trade-offs, in lieu of a deliberative process. Daniels expressed his concern about the direction the SAWG appeared to be taking in informal meetings with functionaries at the CSG, MOH, the EWG and the EcWG.

The SAWG met on October 5. At this point, a new conception of the process was presented to the group, which was convening for the first time. This conception, articulated by Mercedes Juan, head of the CSG and of the SAWG, included a much broader set of stakeholders than the technocratic “insider” direction the group seemed to be following. Instead the SAWG would conduct a social consultation, which might include, as per the draft of the manual presented to SAWG members: legislators, public opinion leaders, NGOs, patient advocates, members of the pre-existing citizens’ network of MOH, doctor groups, provider groups, philanthropists and so on. Furthermore, the SAWG would incorporate the suggestions of the other three groups into a proposal it would submit to the special commission of the CSG charged with recommending diseases for inclusion in the FPGC. Given this conception of the role of the SAWG, the insider status of the group members no longer implied that social forces would be excluded from the decision-making process.

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24 These criteria are discussed in CSG, “Proceso para la Identificación de Gastos Catastróficos,” Presentation, March 24, 2006.
Competing visions of the purpose of a “social acceptability” group have persisted, with the most recent version of the manual simultaneously emphasizing the goal of including social actors, but also of the group’s purpose as primarily to sell the fairness of the process to social actors. As the SAWG met for the first time, healthy discussion ensued about fundamental issues, such as how to start the prioritization process, why prioritization was the best way to organize the health system, and how to make the system seem fair to the inevitable losers. While most of the work of the SAWG was still ahead of them, the deliberation seemed to have moved beyond the notion of trying to use survey techniques to incorporate social acceptability.

**Obstacles to Implementation**

The creation of a fair, or at least a fairer process in Mexico has faced a number of obstacles, but it has nevertheless advanced considerably. Although the search for a fair process was undertaken in order to increase the legitimacy of SP and the FPGC, politicians were also concerned about control. For example, there was the worry that too open a forum for stakeholders would mean health officials would lose control to lobbyists for special interests. One response to this problem which was considered initially was to replace actual stakeholders with a survey, creating the appearance of a fair and open process while preserving control for public health officials. Likewise, the original vision of the role of ethics and social acceptability were quite limited, and the process was designed in a way which marginalized their input. With time, these groups have come to play a more essential role in the process as it is now conceived. Once the idea that a fair process was needed had been widely accepted, a variety of actors began to push for greater openness, which has led to a process that will in fact, if it is implemented, be reasonably fair and open.

The 2006 presidential election has ensured a great deal of continuity in the health system, though it is too early to say how the new president, Felipe Calderón, will alter, if at all, priorities within the health sector. So far, he has chosen to maintain programmatic continuity, raise the budget for the health system, and retain numerous officials from the previous administration who were directly involved in the creation of SP and the FPGC.

Nevertheless, the fair process has still not been implemented, and there continue to be strong incentives for politicians to use non-technical and non-democratic criteria for allocating health resources. Just recently, it was revealed that funds from the FPGC were being used to construct a new cancer institute, the Oncology Tower, the building of which is to begin in early 2007. The funds will come through the FPGC courtesy of a settlement with tobacco. This is, of course, not the purpose of the funding stream represented by the FPGC, which is supposed to pay for disease treatment, not infrastructure development. Without a fair and open decision-making process, however, there will be no real debate about whether this represents the best use of FPGC resources.

As of the beginning of 2007, the greatest threat to the fair process for FPGC was no longer the way the process envisioned by the CSG was conceived. The greatest threat to the fair process was that it would not be implemented at all, so that MOH, or public health officials, or other actors could maintain control of the process. The new administration will have to

decide how important legitimacy is for the FPGC, and how much control it is worth ceding in order to gain legitimation. There are initial assurances of a commitment to implement the process, and the middle part of 2007 should reveal whether this assurance leads to actual implementation. To be continued.