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### Ethics in numbers

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Title:

Ethics in Numbers: Auditing Cleft Treatment in Mexico and Beyond

Abstract:

Plastic surgeons around the globe are implementing projects that mix audit with medical research to ensure and improve the level of care offered to patients with cleft lip and palate. Drawing on recent literature on “audit culture” and the global growth of “performance indicators” as a form of governance, I demonstrate the conjugation of ethics and the production of numerical indicators in cleft treatment. By standardizing documentation, cleft treatment audit programs facilitate Evidence Based Medicine and a form of reflexive self-governance. However, the abstraction that accompanies standardization is amplified as corollary data practices travel. In emerging as “the answer” to improving treatment, these projects “lock out” the politico-economic factors that mediate medical care in resource poor settings. This danger is compounded by the tendency of numerical governance to replace political conversation with technocratic expertise.

Keywords:

Ethics, Audit, Standardization, Cleft Lip and Palate, Reconstructive Plastic Surgery, Mexico

Over the last two decades, craniofacial surgeons have initiated a number of national and transnational clinical audit projects to improve the quality of cleft lip and palate care. At the center of these projects are standardized methods for recording clinical practice and measuring surgical outcomes. Following the outcomes of a European “experiment in inter-center collaboration,” harmonization of patient records across clinical centers is now promoted as a chief mechanism for improving cleft lip and palate care by diverse bureaucratic and professional bodies. These bodies, which range from the World Health Organization to national cleft lip and palate associations, push for standardized documentation to enable (1) the production of a statistically powerful analysis of clinical data and (2) allow individual surgeons and national medical associations to audit their own performance. Cleft lip and palate anomalies are commonly thought of as uncomplicated conditions requiring routine medical intervention. However, as I was reminded by the Mexican surgeons I spoke to, successfully repairing a cleft is “a difficult thing” requiring surgical skill and long term interdisciplinary care. In this article, I examine how the treatment difficulties in cleft care correlates with the introduction of these projects in Europe and their spread through the world. Examining Mexicleft, a cleft treatment audit project that seeks to collect information on clinical practice and to improve treatment outcomes in Mexico, reveals a conjugation of ethics and the production of numerical indicators, which risks obscuring the diverse factors that mediate cleft care.

The increased auditing of cleft care means that a uniform epistemic infrastructure for improving cleft care is now being used across diverse geographical and sociopolitical contexts. The documentation protocol that provides the key material infrastructure for these projects was developed in Europe, in a project called Eurocleft. The protocol, mode of analysis, and understandings of “the problem” they

embody, reflect the European context in which they emerged. To reduce tension between surgeons and ease the clinical implementation of the project, the study leads implemented a set of “minimum records” for all centers, which aligned documentation and allowed for inter-center comparison. While this fostered greater participation, the tradeoff was the richness of the data being collected.

Bringing together recent analysis of audit cultures with Science and Technology Studies (STS) work on standardization, I argue that inter-center cleft lip and palate studies rearticulate good practice in a way that links ethics to numerical indicators. This closes down conversation and debate surrounding issues such as the effects of economic, social, and political influences on therapeutic outcomes. This closing down is supported by the documentation protocols, which have “locked in” an understanding of problems (cleft care lacks Evidence Based Medicine (EBM)) and solutions in cleft lip and palate treatment (audit can rectify this). Following the writing of Callon and Raberharisoa (2008: 246), I understand “sociotechnical lock-in” as the “privilege progressively granted to certain technical and scientific options [which means that] some demands, needs, or expectations cannot be taken into consideration. The know-how and knowledge that would be necessary for them to be taken into account do not exist.” Mexicleft draws on and mimics the Eurocleft study. As a result, the conjugation of ethics and numerical indicators amplifies the “unknowing” caused by audit and standardization.

#### §

This remainder of this article is divided into five substantive sections. I frame my analysis by bringing together two bodies of social science literature – one on audit cultures, the other on standardization practices – that when viewed alongside each other draw attention to the relation between (scientific) abstraction, visibility, and

governance. In the second section, I outline the research methods used to produce and gather the data upon which this account is based. The third section focuses on Eurocleft and its wider adoption and promotion by agencies such as the World Health Organization and national cleft lip and palate associations. The fourth section provides an overview of the Mexican healthcare system and the provision of cleft care in the country. In the penultimate section, I examine Mexicleft, writing about: (a) its appeal to the surgeons that launched it, (b) its documentation protocol, and (c) how it works to discipline doctors. By contrasting Eurocleft and Mexicleft, I aim to expose the possible ramifications of the global adoption of clinical audit as a chief mechanism for improving medical care. What happens when producing EBM becomes an ethical commitment in medical care?

### **Audit, Ethics, and Standardization**

Anthropological studies have shown that the growth of audit practices emerged in tandem with the dissolution of responsibility from the nation-state onto civil society. Less has been written about how audit relies on systemic modes of unknowing – or “unknown knows” (Giessler 2013) – such as the exclusion of social, economic, and political variables in data collection. Mexicleft brings to the fore the centrality of this element of audit practice as it relates to contemporary articulations of professional ethics and good practice in medicine. Like other cleft treatment audit projects, Mexicleft requires participating individuals to utilize standardized documentation protocols and encourages them to assess their outcomes vis-à-vis those of their peers; that is, it encourages and enables self-audit.

Social scientists have investigated audit cultures as “on the make” forms of governance in the neoliberal era (Strathern 2000; Power 1997; Shore and Wright

2000). I suggest that what is “on the make” in Mexicleft and other cleft treatment audit is a unique form of (clinical) research *as* disciplinary regime. In doing so, I expand upon previous studies of audit by drawing attention to what is lost in the picture of the world that emerges from this form of “neoliberal governance”. Audit is often described as political technology, a practice that has been unmoored from its roots in finance and accounting and mutated into a “ritual of verification” (Power 1997) by which people and institutions are increasingly held to account.

Anthropologists Cris Shore and Susan Wright (1999: 558) characterize audit as “a relationship of power between scrutinizer and observed”. Studies of audit often draw on Foucault’s analogical use of the “panoptican” proposed by Jeremy Bentham in which prisoners never know if they are in view of their guards and so act as if they are constantly being watched. In her work on standardization in post-social Europe, for example, Emily Dunn (2005:185) writes that audit “makes production logs into paper panopticons that view and discipline individuals” because of the ultimate knowledge that those in charge of auditing practices may at any time decide to call on a factory’s records.

While I follow these formulations to unpack the mechanisms through which surgeons become enrolled as both “the subjects and objects of knowledge” (Foucault 1993), my interest is how this results in the conjugation of ethics and numerical indicators. The audit projects written about here make an appeal to the scientific conscious of surgeons in order to garner their support and participation. Writing about US toxicology, Kim and Mike Fortun (2005:44) argue that notions of “good science” are embodied in and produced by technological imaginaries that guide “how scientists themselves understand, strategize, and take responsibility for their own situatedness in social contexts”. In their work on scientific objectivity, for example, Datson and

Galison (1992) emphasise that the pursuit of objective knowledge has throughout history itself been a moral act. Through a case study of 19<sup>th</sup> century atlas making in a number of disciplines ranging from astronomy to medicine, they show how although its primary object was cast in terms of truth to nature, objectivity was tied to “an ethos of self-restraint” (Datson and Galison 1992: 92). In Mexicleft and related audit project, such an ethos is embodied and enacted in the completion of standardized clinical records. The standardization of paperwork is central to how projects like Mexicleft work because it allows for the production of a comparable body of clinical data. In this setting, standards govern action throughout the entire clinical process. They demand physicians to conform to the modes of action they engender – taking patient records in line with a standardized protocol – while producing a “scientifically objective” knowledge.

Standards are a central part of contemporary knowledge infrastructures. Following work in STS, I analyze “standards as means to construct uniformities across time and space through the generation of agreed-upon technical rules” (Timmermans 2015: 79). This work demonstrates the centrality of standards to the routinization of laboratory and clinical practice (Timmermans and Berg 2003; Timmermans 2015). Standards play a key role in regulatory practices (Cambrosio et al. 2009) and underscore the manufacture of objective (Timmermans and Almeling 2009) and rationalized (Berg 1997) accounts of the world. Standards prescribe ethics and values (Lampland and Star 2009), allow for the production, collection and mobilization of information between different geographic and epistemic locales (Bowker and Starr 1999), and thus undergird contemporary moral infrastructures (Timmermans and Epstein 2010). They do so, however, through a process of abstraction and exclusion in which select knowledge is used to represent and analyze

the entire context from which it was derived. As medical sociologist Stefan Timmermans (2015: 80) states: “A standard stands in a double relationship to a purpose: it abstracts relevant elements from a broader universe of possibilities by deliberately ignoring other elements, and it has authority to govern social action, regardless of what was left out in the process of abstraction.” Mexicleft provides a unique opportunity to examine how standards travel, how the abstraction, ethics, and values that accompany standardization move between different medical contexts.

Contemporary forms of knowledge production and political decision-making often involve numerical indicators, which are held to represent the lived world and the experiences of people within it (Porter 2012; Scott 1998; Timmermans & Berg 2003). Consequently, political vision is limited in accordance with the interests of decision makers whilst medical and scientific practitioners are encouraged to view and structure their practice in accordance with bureaucratic knowledge ways (Power 1997; Strathern 2000; Timmermans & Berg 2003). My case study demonstrates how an initial, *context specific* attempt to improve medical treatment has emerged as *the global model* for improving cleft lip and palate care. The result is the amplified exclusion of context from the clinical account. Doctors audit their performance through a metric focused on clinical inputs and outputs rather than one that examines the diverse factors that mediate treatment outcomes. As a result, ideas of being a good surgeon focus on metrics rather than, for example, the doctor-patient relationship.

### **A Note on Method**

Between 2007 and 2010, I carried out fourteen months of fieldwork in Mexico to examine how reconstructive surgery is influenced by the intersection of socio-economic variables and national and global approaches to medicine and its



governance (Taylor-Alexander 2014, under review). In 2008, I conducted hospital ethnography in a public institution located in the south of Mexico City. I observed more than 50 craniofacial consultations, carried out 25 interviews with patients and patient-families, multiple interviews with the two lead craniofacial surgeons at the hospital – Dr Ortiz Monasterio and Dr Molina Montalva – and numerous informal discussions with other plastic surgeons working at the reconstructive surgery department. I observed the work of the three other departments that provide care for craniofacial patients – genetics, orthodontics, psychology – interviewing the heads of these clinics and members of the hospital’s research office that worked with them on the development of their clinical research. While I witnessed Mexicleft’s launch, interviewed its central protagonists, and analyze the paperwork at its core, my research focuses on the early stages of the project and its promises and potential pitfalls.

In writing about Mexicleft, I analyze interview data and medical publications within the context of social, economic, and political factors that influence cleft care in Mexico. I examine this material alongside the Mexicleft documentation protocol, focusing on what data is collected, abstracted and excluded through the record keeping template.<sup>i</sup> Upon returning from Mexico, I retrospectively traced the emergence of the project, which led me to examine the global spread of Eurocleft as *the* model for improving cleft lip and palate treatment.

### **Eurocleft: The Global Model for Improving Cleft Care**

In this section I show that the emergence of cleft lip and palate audit in Europe was tied to concerns with the lack of regulation of cleft care and championed as a way to implement EBM in cleft treatment. In particular, the standardization of documentation

was envisaged as a panacea to issues surrounding the lack of EBM and the unwillingness of governments to regulate treatment of cleft lip and palate. Eurocleft was the first project of this type. It harmonized clinical documentation as a means to produce a scientific evidence base by allowing for inter-clinic analysis of treatment outcomes (i.e. medical audit). The project emerged as an international benchmark; it has become necessary for doctors around the world to utilize its documentation protocol in order to produce comparable sets of data and thus allow them to audit their own performance.

Although there are a number of well-established clinical guidelines for the treatment of cleft lip and palate, there is no consensus as to which treatment practices are preferable for each surgical case. The initiator of Eurocleft, Dr. William Shaw of Manchester University, suggests that the lack of evidence – and lack of consensus regarding treatment – can be attributed to three principle causes. First is the large amount of variation that falls under the banner of “cleft lip and palate,” and the variation that exists even between the most common examples. In other words, anatomical frequency and variation are associated with difficulty in establishing facts upon which to base surgical practice. Second, this difficulty has been compounded by the importance of longitudinal analysis for the production of statistically acceptable assessments. Clefts are repaired in various stages, but trying to predict the efficacy of surgical methods based on early treatment outcomes proves unreliable within the pre-existing metric of clinical evaluation. While the efficacy of new medical treatments can often be assessed through (the relatively) quick production of data, such as in pharmaceutical trials, knowledge about the efficacy of cleft treatment requires long-term assessment of patient cases within specific treatment protocols over a period of

up to eighteen years. Third is the need for a large sample size (Shaw et al. 2001; Shaw et al. 2005).

Defining “quality” treatment has been a central difficulty for surgeons seeking to improve cleft care. Working in and alongside institutional cultures in which individuals and collectives base decisions on scientific evidence, Dr. Shaw and his colleagues turned to standardization as a means to overcome the complications of producing facts in cleft care. In the early 1990s, Dr. Shaw began a collaborative study with local and international colleagues. The goal was to do more than assess treatment outcomes. The project team aimed to determine if standardized documentation practices and inter-center clinical audit would improve the quality of cleft treatment and overcome difficulties producing and working from EBM. The initial phase of Eurocleft began in the early 1990s and aimed “to apply a more rigorous methodology to inter-center comparison than was customary at that time. It sought to overcome, at least in part, some of the limitations and potential biases inherent in comparing outcomes reported in the literature from single center reports” (Semb, et al 2005: 64).

Maintaining currently employed treatment protocols was a central component of Eurocleft. It allowed for comparison and analysis of which surgical centers had the best clinical results, while asking for “minimum records” allowed for extant clinical practice to continue. The project worked on an *a priori* understanding that the centers with the best results also had the best treatment protocols. This was not a study of how economic and political factors, or patients’ background, shaped treatment outcomes. These issues were flattened into documents that instead asked surgeons to record for all their patients: type of cleft, time of interventions, and types of intervention. An example of this could be a patient with unilateral cleft lip and palate receives pre-surgical orthodontics at birth, with lip closure at four months using the

Millard method, soft palate closure at nine months using a variation of the Wardill method, and bone grafting and hard palate closure at 8 years of age. Treatment outcomes were assessed through independent phoniatric and orthodontic evaluation and analyzed alongside secondary information such as the total number of patient visits, overall length of orthodontic treatment, days in hospital, and adverse clinical incidences. From here, the authors were able to make evidence based claims about which clinical approaches to cleft lip and palate provide the most favorable outcomes and, in doing so, make a case for inter-center clinical audit as a means to improve cleft treatment care globally.

Evidence Based Medicine grew as a result of concerns that too much reliance was given to the status and experience of medical personnel in the construction of medical authority (Lambert 2006: 2640). Moreover, as sociologists Timmermans and Berg (2003: 3) relay:

According to the ideals of evidence-based medicine, clinical practice guidelines should be based on scientific evidence ... [Proponents of EBM] prefer to remain agnostic as to the reason why something should or should not work - rather, they objectively measure whether or not it works in real life settings.

Significant to note is that the character of EBM was refracted in the Eurocleft study. Evidence was used to make claims about who should be able to perform cleft treatment, to establish what clinical guidelines they should follow, and to encourage governance in the form of audit.

Since the publication of the Eurocleft study, inter-center cleft treatment audit has been promoted on an international scale. The mode of analysis that it promotes, along with the documentation at its core, has become the benchmark for improving

cleft lip and palate care. As the authors of the 2006 WHO report *Addressing the Global Challenges of Craniofacial Anomalies* write:

Professionals entrusted with the provision of health care *have an obligation to review the success of the practices and, where shortcomings are revealed, to take remedial action. Such efforts should constitute a continuous cycle, sometimes known as clinical audit* ... Clinical audit is often divided into evaluating the way care is delivered and its outcomes. Experience in Europe has demonstrated that inter-center collaboration offers significant advantages, by allowing comparison of treatment, establishment of future goals and exchange of successful practices. (WHO 2006: 7, emphasis my own)

In setting out an “obligation” to partake in inter-center clinical audit, the report aligns a professional ethic in cleft care with the production of knowledge of the self. This is knowledge of practice, of clinical inputs and outs, rather than an understanding of what happens in-between, that is, of how clinical practice is mediated by the social, economic, and political status of patients, concomitant health issues, or the conditions in which surgeons provide care.

The WHO report asks that national cleft lip and palate associations reflexively adopt the Eurocleft model and development their own clinical audit infrastructure. However, embodied within inter-center medical audit and the use of “minimum standards,” is an understanding of the problems pertaining to cleft care in Europe and ideas of how to overcome them: doctors are not working from an evidence base, but clinical audit allows both for the production of this evidence and a form of self-governance in an area devoid of political oversight. Excluded from the Eurocleft documentation was any significant analysis of the political, infrastructural and economic settings in which surgeons were practicing or the social environment of

patient-families – for example, their ability to access and continue with care, afford required medications, and avoid exposure to environmental contaminants that could influence the surgical treatment they received. These are all factors that influence cleft treatment in Mexico, as I explain in the next section.

### **Cleft Care in Mexico: The View from Above and Below**

Mexico has a three-tiered healthcare system. The hospital where I carried out ethnography belongs to the public system, which provides care to people who work in the non-tax paying sector. This sector makes up approximately half of the population.<sup>ii</sup> Other Mexican citizens receive treatment through social security (based on payroll taxes), and a small percentage of the population have private healthcare insurance. I met many families that had moved between different healthcare centers before they encountered and settled at the hospital. They spoke to me about the “ugly” experiences they had in other clinics and the vulnerability they felt when their children were placed in the care of rude and disrespectful doctors. Such experiences are not isolated to the field of cleft treatment; numerous studies have examined negative patient experiences in Mexican biomedical institutions (Finkler 2010), especially when they are from low socio-economic or indigenous backgrounds (Molina and Palazuelos 2014; Smith-Oka 2013).

Profound inequalities exist in the quality of biomedical service provision between rural and urban settings, though not necessarily between private and state institutions. Both the public and social security sectors attract (and afford further prestige to) renowned doctors. Reconstructive surgeons work in trying, financially strapped settings and often look to non-profit organizations (i.e. The Smile Train) and pharmaceutical companies to sponsor their daily work. The increased medicalization

of childbirth in Mexico (see e.g. Smith-Oka 2014) means that six out of ten children born with cleft anomalies are immediately referred to government treatment centers (Trigos Micoló 2012). Due to financial hardship, many families are forced either to discontinue or seek alternatives to what can be an eighteen-year long treatment program.

During my fieldwork, surgeons wanted me to explore reasons for patient drop-out. They found it hard to fathom that patient-families would cease care before their full course of treatment was finished. A recent “ecological analysis” found “positive correlations existed between cleft lip and/or palate and socio-demographic, socioeconomic, and pollution factors” in Mexico, suggesting a higher incidence of cleft lip and palate among the most socially vulnerable families (González-Osorio et al 2011:268). Many of the patient-families (usually mothers) I spoke to, relayed to me the financial difficulties associated with receiving ongoing medical care – things as seemingly simple as affording the bus fare to the city. Indeed, one of the greatest fears of these patients was that they would not be able to bring their children to the hospital because of limited financial resources; other families do not have the economic or social capital necessary to gain entrance to public institutions in the first place, as was the case for families I met while accompanying a surgical mission trip (Taylor-Alexander under review).

According to the reconstructive surgeons behind Mexicleft, due to political opportunism and medical negligence, many of the 3,500 children born with cleft conditions each year in Mexico receive inadequate care. I was told that botched reconstructive operations or a lack of follow-up treatment leave many children literally scarred for life. They may be unable to eat well, speak well, breath well and feel well. It is the hands of the state, I was told, as much as the scalpels of surgeons

that is to blame for low quality care: In failing to adequately govern cleft medicine the state continues to jeopardize the wellbeing of children throughout the country. During my eight months of research at the hospital, I was continuously told that treatment outcomes for cleft conditions were inadequate and that the main reason for this is a lack of government oversight, which both encourages and allows unqualified surgeons to operate on the bodies of Mexico's poorest children.

This was the view of the surgeon who headed up Mexicleft while I was based at the hospital, the internationally renowned Dr. Fernando Ortiz Monasterio.<sup>iii</sup> Talking about the project, I asked the surgeon what he considered to be the main difficulties in improving cleft care in Mexico: "Education," he replied, and "too many people jumping onto the wagon, pediatric surgeons, maxillofacial surgeons."

We don't have a system like they have in Great Britain where they say only here and here and here are they going to treat clefts. No one else [is] going to treat clefts, so you can control [the provision of care] easier. This is not possible here, all of these groups are doing it, so I need them to be educated. In the above explanation the doctor ties questions of cleft care to questions of medical governance in a number of ways. He situates the provision of surgical treatment within the context of nation-states, which he implies can be effective regulators of medical practice and surgical practitioners. In contrast to the established mechanisms of control in England, the Mexican state has failed to effectively implement measures that could curtail the causes and continuation of low quality surgery. It thus becomes the responsibility of doctors themselves to make sure that patients qua citizens are receiving the best possible care.

Medical campaigns provide surgical treatment for people that are unable to access hospital based care. The majority of medical campaigns are associated with the



government run *Oportunidades* (Opportunities) program. The official aim of these campaigns is to aid Mexico's rural population both by guaranteeing their Article 4 constitutional right to the protection of health, and in the promotion of general equality (Frenk et al 2004). Although administered by government institutions, *Oportunidades* incorporates and is funded by a large number of different actors, both public and private. This includes individual surgeons from inside and outside of Mexico, state run clinics, NGOs, humanitarian agencies, and large charities including but not limited to Mexican billionaire Carlos Slim's "Fundación Telemex" – the annual donation of the foundation is on average five times that of the total government contribution.<sup>iv</sup>

Like the European study, Mexicleft emerged in the context of a historical shift that has seen the emergence of new forms of state governance. In the form of the medical campaign, Mexico's federal government adopted an approach to providing cleft care to its citizens that centers on harvesting the altruistic sensibilities of medical professionals. These campaigns are usually one or two-week trips carried out by a specialist medical team that travels from an urban hub to an under-resourced, usually rural or semi-rural, location to perform medical operations. After their week or so visit and the performance of numerous operations, the medical teams pack their bags and return home. Doctors often return the following year to the same site, and are able to check the progress of their patients. (I accompanied a team from Utah on one such trip, finding that many patient-families used the campaign as an opportunity to supplement their existing medical provision, while others were able to access services for the first time due to not being able to travel to, or being denied care at, public hospitals). For other teams, each campaign is a one off event – they treat each patient

without any long term plans to assess their progress or provide them with follow up care if necessary. This was a major issue to my Mexican interlocutors.

In their eyes surgical campaigns are often promoted as a matter of political opportunism, privilege quantity over quality, and in their current design often benefit their political organizers more than those they treat. Furthermore, the longstanding rivalry and tactics of members of Mexico's two largest political parties are held to influence the very health and vitality of specific members of the population: those with craniofacial and other anomalies. Here, reconstructive surgeons become unwilling pawns on political chessboards as mayoral candidates and government officials jostle for position and public recognition. For example, Dr. Ortiz Monasterio and the head of orthodontics, both suggested that the campaigns had been incorporated into the ongoing rivalry between Mexico's two major political parties: "These are poor areas, and the PRI says, 'Look, I'm bringing in a group of doctors in order to provide care'," Dr. Ortiz once said, before summarizing, "Campaigns are used as a bit of propaganda by the politicians."

When I asked Dr. Molina, the head of the plastic surgery department at the hospital about his decision to stop surgical campaigns, he first told me that "reconstructive surgery campaigns are probably a model that no longer carries much significance today, in the contemporary Mexico of 2008. It was a very good scheme for rural Mexico in the sixties and seventies."

The articles are a form of publicity used by some public officials, some government representatives in order to justify their work, their presence. There [pause], unfortunately there is a divorce between the numbers of twelve or twenty thousand and the quality of the care. There is a huge divorce in this regard. I personally do not agree with the level, with this type of care. [...]

You could have the best of intentions, be very willing, and with a group of doctors make these week long, perhaps two week long trips every year. But in one week or in two weeks you don't solve many of the problems that the patients are facing.

The commentary offered by this surgeon and his colleague places the surgical campaign squarely within the Mexican political milieu. As struggles for political power become tied to the politics of the body, to the effective governance and administration of populations, certain actors (and actions) come to be seen as more effective, and more ethical, than others. In the next section I analyze the Mexicleft documentation protocol. I argue that it ties ethical action to the production and analysis of standardized clinical records, which in turn lock out the complexities of providing cleft lip and palate care in the country.

### **Mexicleft: A Science of Comparison**

Fellow surgeon, head of clinic, we need you, we are counting on you, Mexico needs your active participation in this field, needs you to continue developing and improving [cleft lip and palate care]. (Trigos Micoló 2012a: 49, my translation)

In the peroration of his editorial in the Mexican medical journal *Cirugía Plástica*, Dr. Ignacio Trigos Micoló celebrates the uptake of Mexicleft in many treatment centers and calls on others to join the project: “Te lo dejamos a tu conciencia” (We leave it to your conscience). In making participation a matter of “conscience” the surgeon hints at the ethical undertones inherent in Mexicleft. The project, as Dr. Ortiz Monasterio relayed to me, encourages cleft surgeons to “be scientists not only craftsman.”

Writing about randomized clinical trials in Sri Lanka, Sariola and Simpson (2012: 565) argue that “Doctors, who might otherwise follow their disposition as healers [...] are no longer operating in craft-mode but are recast as mechanical and meticulous monitors of the body and its functions.” The central role of aesthetics as a measurement of quality in cleft treatment, and the double function of Mexicleft as audit and clinical research, means that a new ethic is being paved in which the aesthetic is made measurable.

As discussed above, since the publication of the Eurocleft outcomes similar inter-center collaboration has been fostered in a number of European and American countries, and is being championed by the World Health Organization as a necessary component in the provision of cleft lip and palate care. At the heart of these projects is a mode of analyzing outcomes that takes for granted, even systemically excludes, the social and political context in which the evidence is being produced: The focus is on what surgical technique and patient management practice is utilized, rather than how context influences medical practice and treatment standards. In this section I show how the fundamental tenants of Eurocleft were adopted as a method for increasing the level of care offered to children with cleft lip and palate in Mexico. In lieu of an “on the ground” account of the project, I provide an analysis of how it was imagined at its inception and of the measurements that it contains. It is important to note that while Dr Ortiz Monasterio and colleagues included additional indicators into the Mexicleft documentation protocol (allowing surgeons to replicate their Smile Train paperwork), its focus remained on surgical methods rather than the infrastructural conditions in which doctors operate, or the social and economic resources of patient-families. It is here that I aim to make explicit the relationship between ethics and numbers, allowing

me to conclude by discussing how the abstraction inherent to standardization is amplified as standards travel.

Ethical judgments in science are often influenced by established sensibilities surrounding good research practice, sensibilities that incorporate ideas about producing a sound science that will benefit the public good (Fortun and Fortun 2005). The same can be said for Mexicleft, which follows the global growth of cleft treatment audit projects as a means to produce a scientifically derived evidence base upon which to govern clinical practice. This mode of improving cleft treatment has been “locked-in” as the Eurocleft protocol and corollary modes of producing knowledge through the data has been disseminated by the WHO and adopted by national cleft lip and palate associations. The result is that the knowledge infrastructure needed to take into account and raise concerns around the socioeconomic variables that influence cleft care has been limited by a focus on “minimum records” and audit as a means to improve cleft care. The model for improving cleft care allows for the making of a scientific evidence base but systemically excludes some knowledge in the processes. As we saw above, this is inherent to the standardization of epistemic infrastructures.

Like its international counterparts, Mexicleft does not call for participant clinics to modify their surgical techniques nor do away with current research. Rather, by standardizing documentation procedures it aims to produce a situation where these techniques (and those using them) can be examined through comparison. The focus is thus on record keeping and clinical audit. As Dr. Ortiz Monasterio told me: “I’m not going to ask you to change anything, do whatever you are doing, but please make records, we need records.” With standardized documentation forming the basis for clinical audit, to quote the doctor, this “documentation is education.” Rather than

attempting to impose certain forms of knowledge onto doctors, it aims to have reconstructive surgeons produce facts in order to educate themselves. The below quote, for example, is taken from an article in the Mexican medical journal *Cirugía Plástica*:

The information gathered at each stage allows you to compare and judge the standards obtained for each patient and for each of the different types and branches of treatment; your own results are then to be compared with internationally accepted quality benchmarks. Everyone knows their own level of results and may analyze and compare their actions and outcomes. (Trigos Micoló 2012b: 109 my translation)

As surgeons act as scientists, producing new knowledge about surgical technique, clinical protocols, and the state of the nation, they are also encouraged to govern themselves. When I asked the surgeon to explain to the objectives of the project, he offered the following:

After ten years or so evaluate your results ... see what your results are like and what mine are like. But we are documenting [our practices and results], speech has to be documented, for example, and you have to evaluate this at particular intervals, at particular years, and by a committee that understands speech development and that isn't involved, etcetera. And so, maybe, I will talk to [a doctor] from Morelia and tell him that my results are better than his, and so, he will have to take notice, no?

In this quote Dr Ortiz Monasterio presents Mexicleft as a method for producing knowledge about the quality of care provided by local surgeons. This knowledge is given its facticity and objectivity through standardized and specialized documentation

procedures. It can thus be used as a form of evidence from which to make truth claims regarding the performance of individual surgeons and clinics.

As accounts from science and technology studies have demonstrated, facts cannot be separated from the social contexts in which they emerge and in order to gain their “facticity” must comply with a number of already accepted criteria, whether numerical or material (Latour 1987). Andrew Lakoff (2005:3) summarizes: “The solidification of a fact requires the ongoing stabilization of the network of actors and techniques through which the fact is produced.” Standardizing documentation allows for the production of truth claims to be made not only because it renders practice visible but because it organizes and produces information in a way that makes it legible and allows it to be mobilized. This in turn allows for direct comparison of center outcomes and with it the ability to exercise power over surgical practitioners.

#### §

In his study of translational medicine and exome analysis, Stefan Timmermans (2015: 80) writes “Trust in standards refers to confidence in the attributes of standards, either by choice or by necessity, to get a job done ... The authoritative nature of standards with implied reliable content and user-friendly characteristics should give confidence that the work is valid and reliable.” While this means that users should not have to worry about the standard itself, “Trust in standards, however, is not an a priori given, but is instead a result from users working with them.” What standards, then, exist in Mexicleft?

The paperwork at the center of Mexicleft is an amalgam of the documentation protocol established in Eurocleft and the Patient Medical Record sheet used by the Smile Train, which has been added to for the purposes of aligning the project with existing record-keeping procedures. This paperwork was incorporated into Mexicleft

because it minimizes the need to produce an extra set of clinical records for the many surgeons who work in clinics sponsored by the charity; and, as I understand it, was also viewed as a way of minimizing any possible hostility or resistance that could undermine the enrolment of surgeons into the program. By harmonizing Mexicleft paperwork with that of the Smile Train, Dr Ortiz Monasterio and his colleagues sought to produce the level of social qua professional harmony needed for the project to be a success.

The Mexicleft documentation protocol contains three main areas of record keeping. The first covers patient background, and includes information about whether there were general complications, and if the mother smoked, consumed alcohol or was exposed to toxins, during pregnancy. In addition, surgeons are asked to note the annual household income of the patient family and the travel time required to reach the hospital.<sup>v</sup> The second focuses on the wellbeing and anomaly of the patient: height and weight of the child, the type and extend of cleft, and whether they were born with any other anomaly are recorded here. Also included here is information about what treatment methods where used to repair the cleft and at what age the patient was operated on. Third, and paralleling the documentation sheet of Eurocleft, is a section that requires three sets of quantitative evaluation: patient satisfaction (with the hospital experience, the surgery itself, and their physicians), physician satisfaction, and speech and orthodontic outcomes. Finally, a “complications form” asks the surgeon to report any incidence of minor or major complication, including patient death; a checkbox list of ten possible contributing factors is contained in this form. This includes the preoperative patient assessment, inadequate technological resources, the labeling and delivery of pharmaceutical medication, communication with patient-families, the training, level, and experience / supervision of the attending personnel,



and any possible environmental influences (that may have led to an infection, for example).

In producing this information and asking surgeons to reflect on the cause of favorable and adverse clinical outcomes, Mexicleft presents the potential to produce valuable information about the correlation between surgical outcomes and social determinants. However, in collecting “qualitative” indicators through checkbox measures, the documentation transforms the social into numerical form – it makes it quantitative. While this opens up the possibility for important epidemiological studies, the inherent socio-economic difficulties of providing and receiving cleft care in Mexico are all but edited away. Troy Porter (2012) offers the notion of “thin description” to characterize what he terms “the aspiration to superficiality” that underlies many scientific and political attempts to understand and manipulate the present. The production of statistics is a central mode of such thinning the world because, as James Scott (1998) has written, numbers underscore bureaucratic modes of understanding.

Sally Engle Merry (2011) and colleagues (Davis et al 2012) write that transparency has become a necessary characteristic of organizations that have charged themselves with the task of helping heal sickness in the Global South. Here, statistics have emerged as a central tool for transforming the translucent into the opaque, for making “legible” (Scott 1998) the performance of individuals and institutions. There are strong similarities between the work of cleft treatment audit projects and the contemporary evaluation of humanitarian agencies by potential donors. Regarding the latter, as Merry (2011) has so poignantly shown, moral judgments are based on outputs demonstrated through numbers. Moreover, while anthropological writing on audit tells of how professionals are increasingly made responsible for governing

themselves, this corollary literature suggests that the global growth of performance indicators threatens to thin out if not altogether replace debate on how to solve the problems of poverty in contemporary capitalism. In producing information on things such as household income and distance patient-families travel to receive care, Mexicleft offers the possibility to provide important insights into the relation between health outcomes and socioeconomic factors. However, it makes the qualitative numerical and thus chances obscuring the overall difficulties involved in providing cleft care in poverty stricken healthcare systems. Here, then, surgeons are increasingly being measured through statistics, through numbers, rather than their attitude towards or relationship with patients.

### **Coda: Ethics in Numbers**

Many Mexican doctors bemoan the low standards offered to especially rural population, locating as cause the policies of the federal government and the altruistic sensibilities of non-Mexican surgeons. Missing from their critiques is discussion of the difficulties treating these communities and the problems encountered when trying to provide top-notch care in what we academics often call “resource poor” settings. The growth of cleft audit projects can be attributed in large part to the difficulties associated with producing sound “scientific facts” in the treatment of cleft lip and palate. Due to these difficulties and the problems they pose for practicing EBM, surgeons have looked to clinical audit as a means for improving treatment methods. Here, ethics is embodied in the production of numbers as a means for shaping individuals and their practice *as well* as a means for living the scientific life. Evidence, audit, and ethics exist in a symbiotic relationship. However, cleft treatment audit projects are premised on a particular understanding of the cause or “problem”

that it seeks to resolve – unskilled surgeons produce low quality care. Mexicleft privileges clinical outcomes above socioeconomic factors and fails to account for the power dynamics that mediate the doctor-patient relationship and other quotidian struggles that Mexican citizens encounter when seeking medical care.

As debate around cleft care is replaced with performance indicators, numbers emerge as “the answer” to improving treatment and thus move attention away from the difficulties of providing medical care in the Global South. It is such discussion that the audit practices at the center of this article threaten to further silence. Audit becomes a kind of “anti-politics machine” (Fergusson 1990) that through the “deployment of statistical measures tends to replace political debate with [the language of] technical expertise” (Merry 2011: S83). This means that instead of raising new questions about how to overcome the barriers patient-families face, and the character of healthcare provision itself, attention is turned to the outcomes achieved by surgeons. Just as the rationalities and technologies of medical-science are central to the clinical management of patients and parents, so to do they direct the ethics and actions of surgical practitioners. Doctors deploy paperwork as a tool for producing knowledge about their peers and about surgical methods, knowledge that can be used to govern practice because it “derive[s] from the rational discourse of science, not the arbitrary values of politics” (Rose 1998:73). This governance threatens to “thin” out the world, editing away the complexity of clinical life in poverty stricken contexts. Here, the ethics of surgeons is measured through statistics rather than how they engage with the difficulties of providing surgical treatment in testing conditions, let alone their attitude toward patients. Being a good, ethical doctor in this setting means entering a world where ethics is construed through performance indicators not through moral disposition or political debate.

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<sup>i</sup> I did not examine patient records – only the documentation protocol itself.

<sup>ii</sup> The introduction of *Seguro Popular* or “People’s Insurance” in 2003 has since quelled out of pocket health expenditure, with 52.7 million people enrolled at the end of 2012 (Smith-Oka 2014); it has been critiqued as an attempt to reposition the Federal state’s constitutional obligation to protect the health of its population, placing the burden on the consumer-citizen (Laurell 2007).

<sup>iii</sup> Dr. Fernando Ortiz-Monasterio passed away in 2013.

<sup>iv</sup> These dynamics do not at all come through in the below analysis; they are vanished by the very character of the projects under consideration.

<sup>v</sup> This economic and travel information is additional to the requirements of the Smile Train’s Patient Information Record, as is the question about toxins.