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## “So, do you like being a treasurer? Yes. What, really??”

At a recent medical dinner, I was asked why I enjoyed being a treasurer so much. It was an interesting question as I currently serve as the treasurer of the British Medical Association and the World Medical Association and as the internal auditor for the CPME, the Standing committee for doctors in Europe. My answer (I was told) was so energetic and enthusiastic that I was asked to write an article on the question. Nothing I am about to say is new or, I suspect, original but seeks to explain why I find money fascinating. I am not a scholar or an academic, (so don't expect too much!) I'm a family practitioner with an interest in finance.

I've always been fascinated by money, not so much in the obtaining or keeping it but in the way it acts, the way it reacts, the way it responds to our activities and how it tells us so much about ourselves.

In just the same way as a microbiologist is fascinated by the behaviour of bacteria – the way they live, the way they adapt, the way they coexist with us and sometimes the profound effects they could have on us as humans, so I am fascinated by the entity we call money. I'm fascinated by the effect our creation can have on us.

For example, in a recent article in the Independent (a UK broadsheet paper) commenting on a survey done by the law firm Slater and Gordon, it was reported that “*A poll of over 2,000 British adults by legal firm Slater and Gordon found that money worries top the list of reasons why married couples split up, with one in five saying it was the biggest cause of marital strife*”. Further it was reported that “*Over a third of those questioned said that financial pressures were the biggest challenge to their marriage, while a fifth said that most of their arguments were about money. One in five of those polled blamed their partner for their money worries, accusing*



Andrew Dearden

*them of overspending or failing to budget properly”.*

The effect money can have on our happiness, our families, our children and often on our health makes me believe it is equally important as a subject of study as any infectious agent.

In very early human interactions, bartering seemed to be the way that we exchanged time, goods and skills. It wasn't long before we began to use intermediary methods to value those things and to then use this as a method of exchange. This intermediary method has included not just notes and coins but a whole host of objects, for example, animals, beads, salt, shells and cigarettes, a widely used and recognised “currency” in

many prison populations.

The importance is not the “thing” but the value we attach to it. For example, in Christopher Columbus's time the value of gold to the Spanish was as a form of currency, the more gold you had the richer you were, whereas it appears that the Aztecs used gold primarily in jewellery and ornaments. They seemed to put greater “monetary” value on feathers, jewels, cotton and they used cacao beans as a currency. (ThoughtCo. *The Treasure of the Aztecs*. Christopher Minster. Sept. 2017).

Though we may smile at this, we do similar things today. For example, we invest in paintings, wine, comics, antiquities, cars and an assortment of other things. In one retirement seminar at which I spoke, one person who attended told me proudly of how he had travelled Europe buying fine wines which would help fund his retirement. When I asked him about his last purchase he told me he had bought a case of 12 excellent bottles of wine. When I asked him how many he had left, he smiled a bit shyly and said “eight”. I informed him this was not so much retirement planning as much as enjoying life.

I find it fascinating that either we learn to control our money or it controls us. In some Christian scriptures, for example, debt is described as a form of bondage. It has been said that we either work for money or we can get money to work for us and so I'm amazed at the number of methods we have created to increase our money, to make it grow. We have devised a multitude of ways with various degrees of risk and, in some cases, legality, in an attempt to increase the money that we have. Whole industries have been created with this single purpose in mind and it has developed its own language and culture. This whole culture around money can be a lifetime's study and pursuit. It can also become an obsession.

I believe it is possible to determine what is important to each of us, what we value and what we feel is important by reviewing how and where we spend our money. If you were to examine your own budget you would see how much money you spend on your home, your garden, your family, travelling, your hobby, etc. You would also see how much of your money (and therefore your time) you give to charitable causes important to you.

Again, when speaking about retirement planning, I often suggest that we review our spending and saving patterns as if we were an outside external person with no knowledge of us personally. I suggest we look to where our money goes, what it is used for and spent on and then form an opinion on what is important to that person, us, and see if it matches our view of ourselves.

I find the way money responds to external factors, for example economic ones, is really a reflection of how we are responding to those things. When the news reports that the markets are nervous they really mean we are nervous, when we are told the markets are panicking they really mean we are. So sometimes we see money as something different to us, something separate as if it had a mind and will of its own, yet in a very basic way, it reflects how we think and how we feel. Many people "stockpile money" feeling this is important, until an impending hurricane, for example, makes them shift priorities and they exchange that stockpile for food, water, batteries, etc.

So, when I look at the accounts of an organisation like the BMA or the WMA, I hope to see what is important to the organisation, by seeing where, and on what they spend their money. Or at least

I would hope to be able to do so. But like the person who claims to love to spend time with the family, but who in reality, rarely does, sometimes it is hard to match our aims, aspirations, our core values and functions with what we spend our money on.

By listening to members of any organisation when they discuss finances you can often judge how members value the organisation by the amount of the willing to pay into it, in terms of not just money but time (personal and corporate), the value they feel they get from membership and over the past few years the changing attitudes of younger people towards organisations. Membership loyalty cannot be assumed from the younger generation in the same way that it could be expected from my generation, for example. One only has to look at how often my children generation change banks compared to mine. (I've had the same bank since I was 17 in case you were wondering!)

Accounts can tell us what we think about risk, member services, teaching, planning or interactions with external agencies. Accounts can tell us how strongly we feel about the statement of the Charles Dickens' character Mr Micawber who stated "annual income twenty pounds, annual expenditure nineteen pounds, nineteen shillings and six pence, result happiness. Annual income twenty pounds, annual expenditure twenty pounds ought (nothing) and six (pence), result misery". For the record, I think the statement to be 100% accurate and financially astute.

We often see money as some sort of external thing, something separate to ourselves, yet it is, in a very real way, a method in which we "express" ourselves. In the same way painters have different styles and different ways to express what they see, I think the same applies to people and organisations and their money and what they value.

But as a final thought, most studies show that money does not make us personally happier in a consistent and constant way, but our relationships do.

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## Regulating the Regulators?



David C Benton



Julie George

*The frequency and veracity questions relating to who regulates the regulators seems to have been increasing in recent years and is a topic of attention in many countries around the world. This paper based on a presentation at the fifth World Health Professions Regulation Conference in Geneva Switzerland addresses this question. Through the use of documentary analysis four specific themes Motivation, Challenges, Tools, and Measurement Dimensions emerged from a diverse range of sources. It is clear that there is a wide range of approaches being taken to the regulation of regulators but unfortunately there is paucity of evidence on the relative effectiveness and efficiency of these methods. After comparing the results from this study with already published work it is appropriate to conclude that if regulators are to live up to the changing requirements of acting in the public interest, they must show leadership in this agenda. By designing robust reliable and valid metrics, transparency and accountability can be enhanced and vulnerability to political whims potentially reduced.*

### Introduction

This article is based on a paper presented at the fifth World Health Professions Regu-

lation Conference in Geneva Switzerland, 2018. Questions like the one posed in the title of this article have been around for two millennia. Indeed, as noted by Uden [1], the first and second century Roman poet and satirist Juvenal posed a similar question "Who guards the guards themselves?" (Quis custodiet ipsos custodes?). However, from a regulatory perspective, the frequency and veracity of such questions seems to have been increasing in recent years and is a topic of attention in many countries around the world [2-6]. The reason for this increased interest seems to be multifactorial. In some cases, such as in the case of the United Kingdom, interest in scrutinizing the performance of regulators has, at least in part, been driven by high profile regulatory systems failures such as those identified in the *Shipman Inquiry* [7]. Such interest is often amplified by intense media coverage [8-10]. In Australia, commitment to a reduction of regulatory burdens and a focus on best practice has played a major role in their reform agenda. Whereas in the United States [11] the need to address the tension that can arise between pursuit of economic market models and public interest protections has acted as a major stimulus. Irrespective of the cause

for this increased interest a more detailed understanding of the topic is warranted if efficient and effective public protection is to be assured. After all, some authors such as Baetjer [12] would have us believe that regulators are not subject to scrutiny, lack accountability and view the existing political processes, designed to hold regulators to account, as ineffective. Accordingly, the time would seem right to more critically examine the issue of who regulates the regulators and more importantly to consider to what effect and purpose they should be regulated.

### Aim

To systematically examine using documentary analysis the approaches taken to holding regulators to account.

### Method

A structured review of the published and grey literature using a variety of search terms combined in a systematic way through the application of logical operators was conducted. To generate the search terms a small group of nurse regulators from around the world were asked to suggest terms that could be used to identify relevant literature. The terms generated were as follows, ((*Regulation OR Regulator OR Licensure OR Licensing*) AND (*Performance OR Accountability OR Review OR Sunset OR Sunrise OR Inquiry OR Evaluation OR Audit OR Governance*) AND (*Nurse OR Nursing*)). In addition, it was suggested that both published and grey literature be searched as it was noted that many of the reviews that have been undertaken by legislative and other bodies are not indexed in the peer-reviewed bibliographic databases. Accordingly, the search terms were used to interrogate *Pubmed*, *Scopus* and *Google* search engines. The Initial yields of papers identified were then reviewed for relevance through scrutiny of the title and abstract. Remaining papers were then retrieved for more detailed consideration.

## Analysis of papers

All retrieved papers were initially read and reviewed for specific relevance to the study aim. Any papers whose substantive content was written in any language other than English was rejected along with those that did not address the study aim. At this stage all those remaining papers were then uploaded to NVIVO 11plus for detailed analysis. All content relating to the oversight, scrutiny and review of the regulatory body, its powers and actions were coded using the general inductive coding method as described by Thomas [13]. This approach is said to offer efficient and defensible procedures for analyzing qualitative data. The method according to Thomas [13] draws on best practices from a range of experts in the field of inductive qualitative analysis and accommodates and condenses large quantities of varied text into meaningful and related themes and concepts. In this case both authors read all the material several times and independently identified content that addressed the aim of the study. Both researchers then compared and contrasted their coded work so as to identify and agree content that formed the basis for the identification of specific interventions and associated thematic categories. Wesley [14] insists that the trustworthiness of the analysis must apply the same degree of rigor as those approaches dealing with the reliability and validity of quantitative studies. To enhance the trustworthiness and precision of the analysis the researchers completed a series of cycles of independent coding, comparing and contrasting their work followed by consensus agreement. However, Tashakkori and Teddie [15] proposed that a triangulation of analysis by the researchers may not be sufficient to assure trustworthiness. Tashakkori and Teddie [15] suggest that any analysis should be augmented and objectified by reference to existing literature. To this end, the results of the analysis was further compared and contrasted with existing literature as part of the discussion section.

## Ethical Approval

As this study did not involve human subjects and was based upon an analysis of publicly available documentary sources the study did not require ethical or institutional approval. Nevertheless, the design and approach used was reviewed by two independent researchers experienced in regulatory and policy analysis. This review confirmed the appropriateness of the planned methodological approaches and procedures to be used.

## Results

A total of 3723 papers were identified and after review of the titles and associated abstracts one hundred and fifty eight were retained for retrieval and further analysis. On closer consideration of these papers a further eighty seven papers were rejected. Of those rejected, nine were published in a language other than English and the remainder either did not focus specifically on the study aim or were opinion pieces. This left seventy one papers for detailed review and analysis.

The papers fell into four categories. The most frequently found (n=39) could be classified as sunset or legislative reviews where the functioning of the regulator was under scrutiny by the establishing or accountable oversight body. However, there was no consistency to the topics addressed by these reviews. Nor did the reviews follow any standard structure, analytical approach or reporting format. The next most frequent type of publication was independently funded reviews by policy think-tanks or philanthropic organizations (n=16). Most of these papers were proponents of a market based model of regulation and frequently advocated for deregulation. A few research studies in peer reviewed journals were identified (n=10). These covered a range of relatively narrow aspects of performance such as the efficiency of notification of the National Practitioner Data Bank [16]. The

least frequently found papers (n=6) were collations of suggested best practices produced by inter-departmental or intergovernmental bodies such as the Organization for Economic Co-operation and Development [17].

## Thematic Content

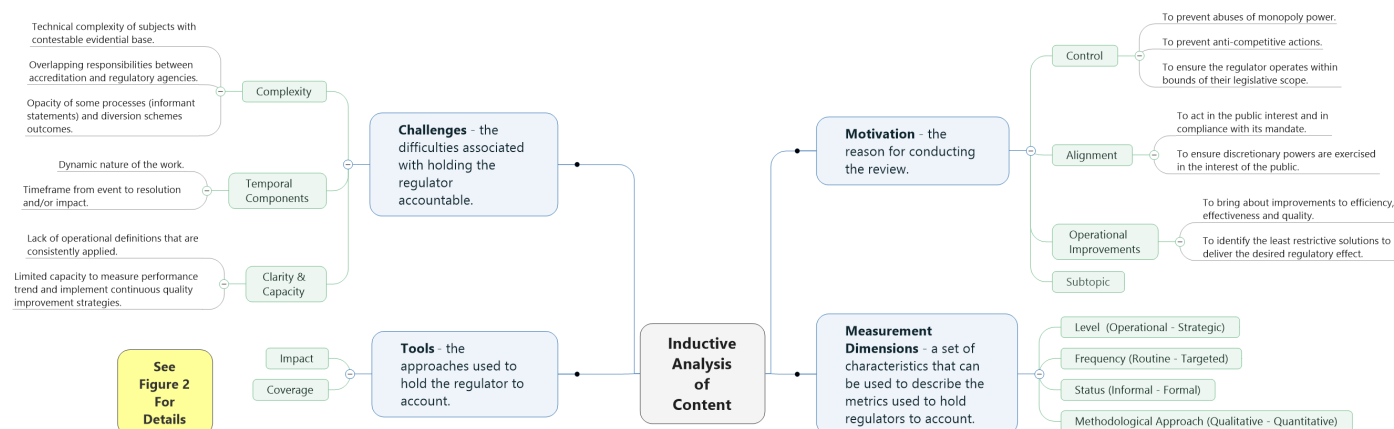
Four specific themes emerged from the analysis, *Motivation*, *Challenges*, *Tools*, and *Measurement Dimensions*. Each theme had several sub-themes and accordingly these are reported in detail. Figure 1 provides a synopsis of the composition of each of the themes.

### *Motivation*

Irrespective of the type of publication, all papers offered an explanation of why it was necessary to undertake the review of the regulatory body or its functions thereby specifying the *motivation* behind the work. Closer examination of this theme identified that the motivating factors could be classified under three main topics – *control*, *alignment* and *operational improvements*. In the case of *control*, the motivation related to ensuring there was no abuse of power granted to the regulator and that they remained within the bounds of the purpose and responsibilities delegated to them by their establishing legislation. *Alignment* was more specific in ensuring that the actions of the regulators were in step with their public protection mandate. *Operational Improvements* were far more narrowly defined and addressed specific aspects of the performance of various functions as well mechanisms to improve efficiency, effectiveness and quality of the services being delivered.

### *Challenges*

Multiple references in the documents were identified, which highlighted the challenges associated with holding regulators to account. These challenges are classified under the three sub-themes of *complexity*, *temporal*



**Figure 1.** Themes from the Inductive Qualitative Analysis of Documents

*components* and *clarity & capacity*. Measuring the performance of regulators can be complex as it is only recently that robust research into the topic has been conducted. Also the fact that there can be both internal and external overlapping responsibilities can make determining accountability more challenging. For example, in the case of an internal overlap where a board of nursing is part of an umbrella structure and it does not have control of some of its key resources such as their investigators. Consequently, it is difficult to attribute accountability for both success and failure. Similarly, in the case of educational program approval where the Department of Education requires accreditation to be conducted and the board of nursing has overlapping program responsibilities determining how these differing approaches interact can be complex to unpack. The *temporal component* refers to the time taken to identify and resolve issues. Sometimes there can be criminal procedures taking place in parallel with the investigation of conduct or performance complaints. Ensuring a speedy resolution can be a challenge. Finally, the difficulties of precisely specifying clear measures that are robust, reliable and valid can, along with the relevant board and staff capacity to interpret and respond to the findings, present leadership of the organizations as well

as any oversight entities both operational and strategic challenges. For example, increasingly boards of nursing have enormous amounts of digital data that relate to their core purpose yet the analytical capacity to interrogate and interpret such material may be limited or in some cases entirely absent.

### Measurement Dimensions

From consideration of the various reviews conducted it is possible to identify that the measures used to hold the regulators to account are multidimensional. While the studies do not frame the measures used as a set of polar-opposites it is a useful way to consider the evidence identified. As can be seen from Figure 1 there is a framework of four dimensions that can be used to classify measures that can be used to hold the regulator to account (Level, Frequency, Status, and Methodological Approach).

A wide range of tools, techniques and procedures were identified as being used to hold regulators to account. Some of these are general in nature and amenable for use across a range of responsibilities. Other approaches were far more specific and addressed a single aspect of the board's functioning. Collectively these two aspects can be used to delineate the *coverage* of the spe-

cific tools, techniques and procedures used (Figure 2). In addition, the potential *impact* of these approaches could be further classified as being either weak or strong.

Although it is not illustrated as part of Figure 2, it would also be possible to further classify these interventions as either routine or ad-hoc, as well as being internally or externally focused. These classifications are congruent with the dimensions already noted under the measurement theme.

## Discussions

It has been reported by Baugas and Bose [18] (2015) that 36 of the 50 US states have some form of sunset legislation providing regular scrutiny to the laws that govern regulation and other controls on services offered to citizens. In some cases, the sunset review is mandated on a regular cycle whereas for other States it is an optional power that the legislature can bring into play when necessary either due to specific performance problems or in some cases due to political exigencies. It is clear from the results presented in this paper and the findings of Baugas and Bose [18] that this is a common approach used to scrutinize the performance of regulatory bodies. However,

Coverage	Specific	<ul style="list-style-type: none"><li>• Complaints</li><li>• Regulatory Impact Assessment</li><li>• Peer Review</li><li>• Freedom of Information Request</li><li>• Benchmarks with Best Practices</li></ul>	<ul style="list-style-type: none"><li>• Judicial Reviews</li><li>• Media Reports</li><li>• Board Appointments/Removals</li><li>• Audit Reports</li><li>• CEO Appointments</li><li>• Organizational Competence/Scope</li></ul>
	General	<ul style="list-style-type: none"><li>• Annual Reports</li><li>• Parliamentary Committees</li><li>• Lay Board Member Appointments</li><li>• Consultation Requirements</li><li>• Giving Reasons for decisions</li><li>• Publishing Minutes</li><li>• Webcasting meetings</li></ul>	<ul style="list-style-type: none"><li>• Ministerial/Governor Direction</li><li>• Funding Control</li><li>• Sunset Reviews</li><li>• Super-Regulators</li></ul>
		Weak	Strong
Impact			

Figure 2. Current Approaches to Holding Regulators to Account

the non-standardized methods used, the irregularity of frequency, and inconsistency of reporting means that it is difficult to track improvements over time or provide opportunities for comparison between regulators. These comparisons could be across regulators in the same jurisdiction or for specific regulators that regulate the same discipline across jurisdictional boundaries. This variability, while in some cases addressing defined concerns, denies legislators and the regulators themselves an opportunity to benchmark and learn from optimum practices.

One approach to address this problem would be to attempt to generate a normative movement through conducting an integrative review of the sunset reports and their associated guidance so as to identify best or at least promising practices that could then be followed.

An alternative way to address variability would be to use the finding of this study to design a set of regulatory metrics that are cognizant of the challenges identified and utilize sound measurement design approaches. The resulting, clearly defined

metrics can then be uniformly gathered so comparisons both within and across jurisdictions would be possible. The addition of such metrics to the plethora of tools and approaches already in place would potentially add value to the many existing efforts of holding regulators to account. Again, the production of such measures, ideally through a collaborative-based generative approach would provide an opportunity to take advantage of the normative impact of developing standards of best practices. Ultimately, based on the experience of the National Council of State Boards of Nursing Commitment to Regulatory Excellence[19] (CORE) program, this approach should provide opportunities for increasing efficiency, effectiveness, transparency and accountability of the regulator. A more radical approach, but one that may be viewed by the legislators as being more proactive, would be for regulators themselves to develop and implement an accreditation system where peers provide expert commentary against a set of well defined standards of best regulatory practices.

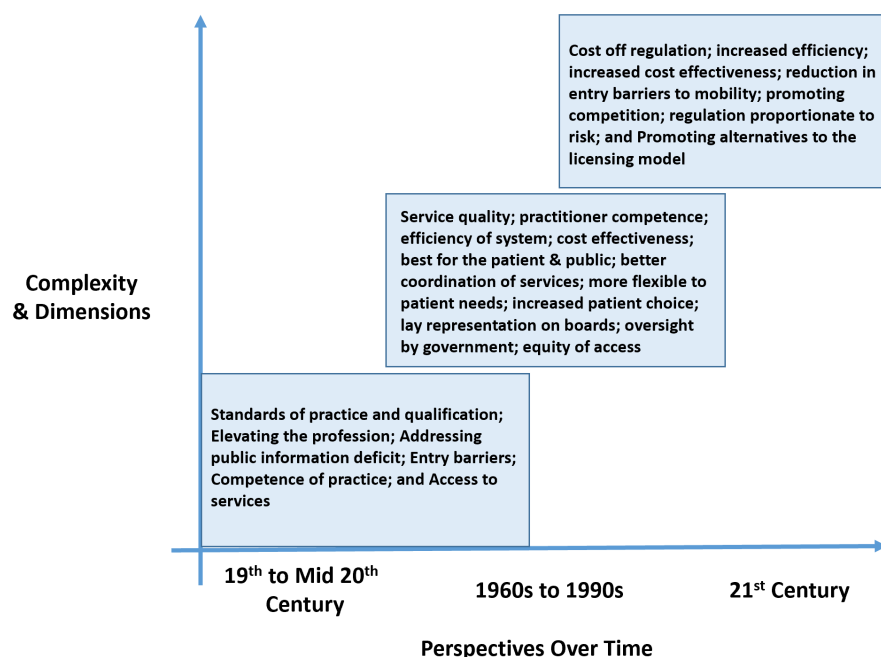
Work by others have identified that the dimensions of regulatory accountability have

been changing. Some authors [20-22] have explored and documented how professional regulation has changed over the years. A closer look at their work enables a synopsis of key features of how the concept of acting in the public interest, captured in the three boxes, has evolved both in terms of increased complexity and additional dimensions (Figure 3). Identification of these dimensions potentially provides a useful basis for augmenting the findings of this study in developing evidence based approach to the review of regulators.

In recent years, at least in the nurse regulatory space some attempts have been made to identify and use more robust, reliable and valid performance metrics. Benton et al [23] in their global Delphi study identified a multi-dimensional framework for the performance assessment of nurse regulators. Indeed, this framework was subsequently used by Clarke et al [24] across five different disciplines (medicine, dentistry, midwifery, nursing and pharmacy) in Cambodia to benchmark and contrast their relative performance as a means of seeking opportunities for quality improvement. More specific interest into addressing the question of to what extent are the administrative structures of regulatory boards having an impact of efficiency, effectiveness and public safety is also being addressed [25]. The work of the Washington State Care Quality Assurance Commission [26], North Carolina General Assembly [27], Benton et al [25], and Benton and Rajwany [16] are all congruent with the wider recommendations of the Organization for Economic Co-operation and Development [17] highlighting the advantages in terms of effectiveness of assuring the independence of regulatory bodies who advocate for a proactive approach to performance review.

### Conclusions

This study demonstrates that Baetjer [12] view of regulators being unregulated is far from the truth. There is already a wide range



**Figure 3.** Changing Features of Acting in the Public Interest

of tools being used. However, we agree with Baetjer [12] in his contention that there is, as yet, no robust and consistent approach to regulatory performance review. Variabilities in approach, frequency and measures result in a sub-optimum patchwork of findings. Despite there being a wide range of approaches to the regulation of regulators there is currently a paucity of evidence on the relative effectiveness and efficiency of these methods. Regulators both within the same discipline, across jurisdictions, as well as those from different disciplines, within the same jurisdiction, need to collaborate to standardize performance metrics. Such collaborations could generate data collection methods that subsequently could offer the basis for the identification of best practices to optimize and systemize the pursuit of regulatory excellence. Accordingly, if regulators are to live up to the changing requirements of acting in the public interest, they must show leadership in this agenda. By designing robust reliable and valid metrics, transparency and accountability can be en-

hanced and vulnerability to political whims potentially reduced.

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## Patient-reported Indicator Survey (PaRIS): Aligning Practice and Policy for Better Health Outcomes



*Luke Slawomirski*



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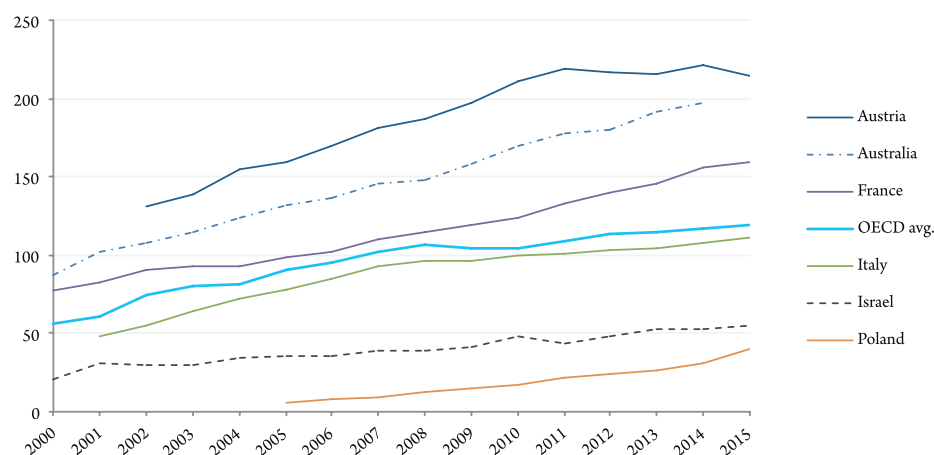


*Sunita Karmakar-Hore*

Medical professionals and healthcare practitioners are fundamentally motivated to

help patients improve their health and limit the impact of their illness. Achieving this

in a way that respects the patient's dignity, as well as their preferences and values, is



**Figure 1.** Total knee replacement rates per 100,000 population in selected OECD countries and the all-OECD age-adjusted average, 2000–2015

Source: <https://stats.oecd.org>

Note: National average of 29 OECD countries adjusted for increased life expectancy (reference year: 2000)

the underlying reason – and the intrinsic reward – for choosing a profession in the challenging and demanding field of health-care.

Given the global trend of increased expenditure on health care as a share of national income, it is therefore surprising that systematic, empirical measurement of the outcomes and experiences of care from the patient's perspective is still the exception in most healthcare systems across the world [1, 2]. This gap in knowledge limits the ability for evidence-based policy making and value-based health care, which aims to maximise benefits of health care at an acceptable cost (including opportunity cost of alternative investment of these resources).

This knowledge-gap impacts medical practice in two crucial and related ways. First, healthcare providers lack information on the effect of their work on factors valued by their patients such as pain, function, independence, and being treated with compassion and respect. Second, this lack of information is a missed opportunity to frame

clinical activity around the person in front of you – to ask 'what matters *to* you?' rather than 'what's the matter *with* you?' [3] Better information on outcomes and experiences of care is also needed by policy makers trying to reorient the healthcare system to meet the needs and expectations of the communities it serves.

In this paper we seek to describe the current shortcomings of measurement in health care, what changing this means for medical practitioners, and how the Patient-Reported Indicator Survey (PaRIS) – a new OECD initiative – can help health professionals measure what matters to their patients.

## Outcome Measures Miss a Very Important Perspective: the patient's

Medicine is fundamentally a scientific endeavour and, like all sciences, based on empirical measurement and observation. Many metrics are collected in health care but not

always those that tell us about of the impact of care on patients' lives. The problems with traditional measurement in health can be distilled to three concerns.

### One: we confuse outputs with outcomes

The number of procedures performed or drugs prescribed are commonly measured. But these describe outputs not outcomes. While they have their use in some contexts, they are inconsequential to the outcomes of interventions.

For example, the age-adjusted rate of total knee replacements in OECD countries has more than doubled since the year 2000, rising from 55 to 119 per 100,000 population (Figure 1). Rates vary more than 4-fold between countries, and similar variation is also observed *within* countries by hospital or geographic region [4]. Such differences provoke questions about the value generated for patients, and for communities that pay for these procedures, which are expensive, involve a lengthy and painful recovery period, and are not without risk. Which rates are justified by commensurate patient outcomes compared to other treatment modalities? What proportion of patients experience an acceptable improvement in their pain and symptoms? How many experience improved mobility, and to what extent? In the majority of countries we do not know. A recent US study of about 4,000 patients who underwent total knee replacement suggests that most experience no improvement in their symptoms [5]. But systematic data across entire healthcare systems are rare.

Readmission and revision rates following knee replacement – outcomes that most patients wish to avoid – are often measured but shed little light on the other important outcomes: less pain and better function. These data can't be harvested from administrative information systems but must be

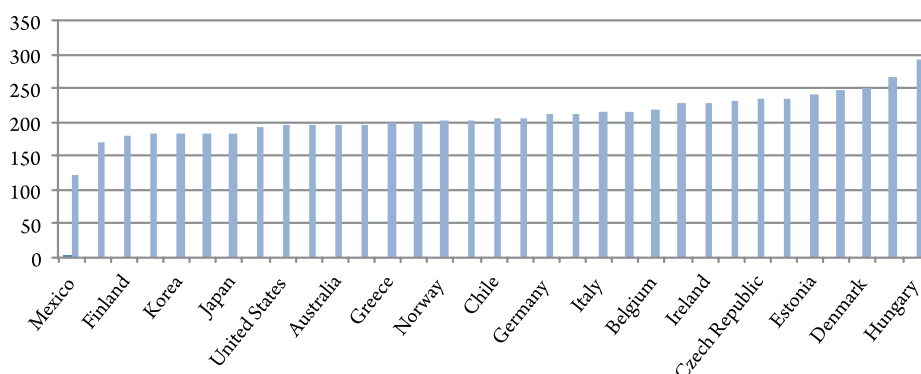
collected from patients themselves, and are needed to answer important questions about effectiveness and value.

## Two: 'hard' outcome metrics have their limits

Certain outcome measures, while useful and informative in some instances, are too blunt to capture the subtle effects of many medical interventions. For example, in addition to readmission and surgical revision metrics, mortality outcomes are commonly used in some sectors and specialties. Patient suicide is an important sentinel metric, but only one of several indicators to help us understand how well mental health programs are working. Patient-reported anxiety and depression, sleep quality and social health status are softer but equally important metrics that should be collected systematically to inform practice and policy.

Survival or mortality rates are traditionally deployed as the prevailing outcomes for many pathologies. But these lack the granularity and responsiveness to tell us how well treatments are working at the individual level. People diagnosed with cancer highly value surviving the disease – but when these patients and their families are asked, it is clear that therapeutic 'success' entails more: pain control, retaining independence, ability to sleep and perform normal activities of daily living [6, 7]. Yet, measuring the effectiveness and the value of cancer treatment rarely extends beyond mortality [8], despite the convergence on these measures in recent years (Figure 2). In a growing number of pathologies survival lacks sufficient sensitivity to differentiate between therapies, regions, hospitals or other units of measurement – little separates the best from the rest [9, 10, 11].

This evolution is also a cause for celebration – modern medicine has become so



**Figure 2.** Age-standardised mortality from cancer, 2013

Source: <https://stats.oecd.org/>

good at treating this disease that it now limits how much we can learn from mortality statistics. To explore the full impact of treatment on the patient, other outcomes need to be considered. Men with prostate cancer, for example, place high value in preserving erectile function and avoiding incontinence – outcomes for which the survival metric cannot capture and which require direct input from the patient [12]. Other outcomes valued by patients receiving treatment for a range of acute and chronic conditions include self-rated health status, fatigue, limitations on daily activities and bodily functions.

## Three: the patient experience matters more and more

The experience of care is important for all patients, especially the growing cohort with multiple chronic conditions who need to manage their health over time and with the help of a range of healthcare providers. The care experience includes being treated with respect and compassion, being supported, listened to and involved in decision making; it also means that care is integrated across teams who communicate with each other and with the patient. A good experience of care is an important end in itself especially for patients with complex health needs for whom navigating a fragmented health sys-

tem is challenging, frustrating, time consuming and costly.

A positive care experience is also associated with better clinical outcomes, and is a strong signal of a well-run healthcare practice or organisation [13, 14, 15]. While in some sectors of care, such as palliative and end of life care, dimensions of the care experience – compassion, dignity, respect of patient and family wishes – arguably comprise the most important, alongside pain control, for patients and their loved ones. While considerable progress has been made in some places, the care experience is not captured systematically or routinely compared to other healthcare metrics.

## Patient-reported measures are an opportunity to improve practice and optimise results

Patient-reported outcomes and experience measures – PROMs and PREMs – can enable clinicians to improve their practice, communication and outcomes in several ways [16]. Nevertheless, many practitioners are anxious about collecting these data from their patients and about the way in which these data may be used. In our discussions with providers, practical and professional

issues are often cited including additional clinical and administrative burden, the validity and reliability of these metrics, their use in pay-for-performance (P4P) schemes, and the jettisoning of useful existing metrics.

## Patient-reporting can improve clinical practice

Collecting PREMs and PROMs may seem like additional work for providers. However, given the benefits, it should not be viewed that way. Rather, collecting these data should be seen as part of good practice – as routine as taking a sound history and vital signs. PROMs especially can add more structure and rigour to the oral history during initial and subsequent consultations, yielding valuable clinical information that enables care tailored to individual patient needs, especially in complex cases. One randomised study found that during chemotherapy, regular patient-reporting of symptoms such as pain and nausea was associated with significant reductions in emergency department visits, better quality of life and longer survival [17, 18].

Shared clinical decision making can be difficult for providers and patients, even for patients with higher socioeconomic status [19]. PROMs and PREMs can enable more effective partnering between providers and their patients, particularly for preference-sensitive care [20, 21]. Decisions may also be based on aggregated outcomes and experiences of other patients. As a result, clinical conversations change, and care cycles pivot to what patients need and prefer. Aggregated PREMs and PROMs data are also an opportunity to monitor and improve practice and policy at a system level over time, through meaningful benchmarking across organisations [22]. The data can be used to develop and update clinical guidelines and decision-support tools.

Rather than increasing clinical workload, jurisdictions implementing routine PREMs and PROMs collection are reporting that this can actually streamline clinical processes and the flow of information [23, 24, 25]. Data submitted by the patient prior to a consultation identifies in a structured and consistent way their clinical status and needs. This information is useful for triaging patients, and better preparing the clinical team. Using digital tools like smartphone apps or web portals can further streamline this process, and enable the patient to provide their data at their convenience. Linkage with electronic health records means that information is delivered directly to the practitioner's desktop with minimal delay [26].

Nevertheless we do acknowledge that the number of metrics collected by providers has grown over the years. Calls are heard to modernise data collection methods, improve information feedback to providers and patients in addition to rationalising the amount of measurement required and to focus on what truly matters [27]. However, we would argue that PREMs and PROMs are indispensable metrics that should be routinely collected. Use of the right state-of-the-art technology could greatly reduce administrative burden, and with enough interest and investment data collection could become partly automated in the future. For example, a patient's mobility can be uploaded from a wearable device or smartphone, rather than manually reported in paper or electronic form. This would not only reduce the burden but also boost the quality of the data.

## Patient-reported measures are valid and robust

The validity and the sensitivity of PREMs and PROMs is often questioned as is their ability to discern the influence of a clinical intervention from other factors that

influence outcomes. On the first point, the development and validation of the various tools to measure outcomes and experience from patients is decades old. PROMs have undergone rigorous psychometric testing and statistical validation, with results published in the peer-reviewed literature. The evidence for disease-specific and generic tools measuring what is intended in a valid and objective way is sound [28]. Data are collected at various time points throughout a patient's care, or pre- and post-intervention, reducing recall bias by eliciting responses for the various dimensions and outcomes of interest at the time of reporting. PROMs instruments for a specific condition or intervention seek scaled responses in the relevant dimensions (e.g. pain, anxiety, function and mobility) in a standardised, unambiguous way. Many have been translated into various languages and validated across a number of countries, in order to take linguistic and culture nuances into consideration.

PREMs also are now sophisticated and sensitive, beyond the patient 'satisfaction' surveys that many providers may have encountered in the past. They elicit scaled data across a range of dimensions including accessibility, communication, continuity and confidence. These data are now used to inform assessment and international comparisons of health systems [29].

Some factors that influence the outcomes of care – patient behaviour, adherence to treatment as well as age and comorbidities – are beyond the clinician's control. However, this problem can be attributed to *any* metric. Readmission, death and infections are all subject to these confounding variables. Singling out patient-reported measures specifically in this manner is arbitrary. And like any data that are reported and benchmarked, confounders for patient-reported indicators can and should be adjusted for in order to make meaningful comparisons [30]. This is also a way to correct for differ-

ent response-tendencies between groups of patients.

## **The goal is to facilitate learning and improvement**

On the question of P4P, collecting and reporting these data would help learning and improvement. P4P is being tested in many healthcare systems, but the evidence on what financial incentives work best in improving 'performance' is not clear-cut [31]. Numerous reasons exist for this. As previously noted, a fundamental motivation for medical practitioners is the desire to improve their patients' lives. Financial incentives are difficult because they often focus on individual elements to be rewarded, and may lead to clinicians focusing on certain elements of their care only, while good care is a product of individual, systemic and organisational factors.

With P4P, it is also difficult to reflect the inherent complexities of modern medicine which, in highly functioning systems, is the product of an integrated healthcare team involving numerous practitioners and support staff working within and across organisational boundaries and communities over time. It has proved difficult to design a scheme that effectively and equitably targets financial rewards or penalties [32, 33]. Providing feedback and information on various dimensions of 'performance' stimulates continuous improvement across health care teams [34]. This, of course, should include information reported by the patients receiving care.

## **Patient-reported measures will complement – not replace – existing outcome indicators**

While traditional outcome metrics such as mortality or hospital readmission have their limitations, they also have an important place in informing policy and practice.

For many diseases and interventions, these metrics remain valuable for making clinical decisions and monitoring performance. PREMs and PROMs are meant to complement – not replace – these important indicators.

We also wish to point out that reporting and benchmarking traditional outcome metrics – such as standardised mortality rates – were also resisted when first introduced. However, with time they have become an accepted outcome measure. The richness and granularity of health care evaluation would be greatly enhanced by also including information reported by patients.

## **How can an international initiative like PaRIS help practitioners?**

In January 2017 OECD Health Ministers met in Paris to discuss the next generation of health reforms. These discussions revealed clear political momentum to pay greater attention to what matters to patients. The resulting Ministerial Statement [35] calls on health systems to become more people-centred by developing international benchmarks of health system performance as reported by patients themselves. The statement makes clear the nexus between the core objective of medical professionals and policy makers – between policy and practice.

Taking forward this mandate, the OECD launched the Patient Reported Indicator Survey (PaRIS) initiative. PaRIS aims to build international capacity to measure and compare care outcomes and experiences as reported by patients, using indicators that enable comparisons across countries. It also aims to encourage patient-reported measures to evolve in a common direction internationally, to enable shared learning, development and research.

## **PaRIS hopes to advance by accelerating routine adoption**

Up to now, routine collection of patient-reported measures has been predominantly led by forward-thinking clinicians and health services. Collection of PROMs in specific conditions like cancer or osteoarthritis is growing in a number of countries. An objective of PaRIS is to support countries where such initiatives already exist to accelerate the routine adoption and reporting of validated, standardised, internationally-comparable patient-reported measures, and to disseminate useful learnings and insights to other countries wishing implement PROMs. It is also to encourage development of common metrics and indicators that can enable comparisons and learning at national and international levels. OECD has established international working groups comprising clinicians, patients, academics and policy makers to develop patient-reported indicators suitable for international comparisons in elective arthroplasty (hip and knee), breast cancer and mental health, with the ambition to report commence reporting in 2019.

## **An information gap needs to be addressed**

The proportion of people in OECD countries who suffer from one or more chronic condition is growing. This cohort does not fit neatly into one disease category and most receive routine follow-up care in primary care or other ambulatory settings. Often, different providers are involved and people must navigate fragmented, un-coordinated care. The result is substandard care, and systematic data for this group of patients is virtually non-existent.

PaRIS is therefore developing a new international survey on outcomes and experiences of patients with one or more chronic conditions. This new survey will

measure both PROMs and PREMs including health status, pain, fatigue, function, anxiety and depression, access, communication and care continuity. Indicators will be selected on the basis of criteria such as reliability, validity, relevance, feasibility and fitness for use. The survey will make variation within countries visible. Together with other data, this will help shed light on variations in care and how successful healthcare systems and organisations are in responding to the needs of this important group of patients.

## A rising tide can lift all boats

How can country-level reporting and benchmarking of patient-reported indicators influence grass roots clinical practice? OECD collects a range of indicators, many of which concern the quality and outcomes of care. Some of these – cancer survival and hospital readmissions – have been discussed above. The aim of international reporting of these, like any other indicator, is not to create league-based tables but to flag areas of care that may need greater examination and drive quality improvement strategies. Each country runs its health system in a unique context, based on its own priorities, values and resourcing constraints. The value of international reporting lies in the provision of accurate, timely and consistent information on a range of structural, process and outcome measures that is critical to the effective governance and functioning of *any* healthcare system.

Practice and policy should be based on solid evidence and continuous measurement. OECD provides a forum for countries to learn and to improve the way these data are collected and indicators are generated. Numerous examples exist where improved data collection at the country level has generated tangible benefits.

The objective of PaRIS is no different. Its aim is to help participating countries build

their internal capacity to reliably measure this very important dimension of health care, and to deploy this information for continuous learning and improvement in clinical practice to policy. Countries are at very different stages of implementing patient-reported measures, and PaRIS provides a platform and a set of tools to achieve the necessary transformation – a rising tide that can lift all boats.

Many outputs are measured and reported in health care. However, metrics on improving health, limiting the impact of disease and experience of care are currently lacking. The systematic collection of this information through PROMS and PREMS is an important lever to meet the needs and expectations of patients in an increasingly complex and challenging environment. The OECD PaRIS initiative aims to help countries institute consistent and reliable collection of patient-reported measures across their health systems.

Healthcare practitioners and providers have much to gain from collecting and using patient-reported measures if implemented in concert and with proper support from administrators, health system managers and policy makers. PROMs and PREMs can and should be part of routine patient care, as a robust way to gather information from patients to better inform their clinical care and improve the health system for the benefit of patients, providers and societies.

*Disclaimer:* The opinions expressed and arguments employed herein are those of the author and do not necessarily reflect the official views of the OECD, CIHI, or of the governments of OECD's member countries.

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## Physician Complicity in Capital Punishment

### Violating the ethical obligation to do no harm

Following the violations of medical ethics committed by physicians during the Nazi regime and immediately after the Nuremberg revelations, the World Medical Association adopted two documents that embodied the Hippocratic Oath and asserted

the prohibition of physician complicity in antihumanitarian acts.

The **Declaration of Geneva** affirms the medical professional's pledge "to dedicate their lives to the service of humanity" and "to

not use medical knowledge to violate human rights and civil liberties, even under threat".<sup>1</sup> The **International Code of Medical Ethics** sustains the physician's duty to provide "competent medical service in full professional

<sup>1</sup> WMA Declaration of Geneva, 2017. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-geneva/> on August 17, 2018.



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and moral independence, with compassion and respect for human dignity”.<sup>2</sup>

These documents not only make it explicit that medicine is a therapeutic and compassionate field but also that the medical professional has a duty to uphold medical ethics in the face of contravening laws or regulations. This idea is portrayed clearly in the **WMA Council Resolution on the Relation of Law and Ethics**.<sup>3</sup> It follows then that physician involvement in the administration of capital punishment is ethically proscribed because it violates the ethical principles of the profession.

In the Islamic Republic of Iran, physicians have been implicated as complicit in the sentencing of persons convicted of crimes committed as juveniles (below the age of 18) to the death penalty. In June 2018, a

19-year old Iranian teenager was executed. His sentence had been issued based on an official medical opinion that he was “mentally mature” at the age of 14 when the crime of which he was convicted had taken place. In its verdict, the court cited an expert medical opinion from the Legal Medicine Organization of Iran, which stated without explanation that he had gained “full maturity” at the age of 14.<sup>4</sup>

Most crucially, this teenager is the fourth individual since the beginning of 2018 to be executed after being convicted of crime committed when under the age of 18. There are at least 85 other juvenile offenders who currently remain on death row based on medical maturity assessments.<sup>5</sup>

The issue of concern is twofold. Firstly, such physicians are complicit in the administration of capital punishment, which as mentioned is a direct violation of their ethical duties as medical professionals.

Secondly, it is a matter of violating the rights of a child, by both physicians and the Iranian government.

Under international law and in accordance with international principles of juvenile justice, including articles 17.1 and 17.2 of the **United Nations Minimum Rules for the Administration of Juvenile Justice (“The Beijing Rules”)** [6] and the **International Covenant on Civil and Political Rights**<sup>6</sup> to which Iran is a State Party, the use of the

death penalty against people who were below the age of 18 at the time of the crime they are convicted of committing is absolutely prohibited.

The decision of countries such as Iran to continue to administer the death penalty among persons who committed crimes as juveniles is also in direct opposition to the Convention on the Rights of the Child,<sup>7</sup> which Iran has ratified. This Convention writes: State parties shall ensure that: No child shall be subjected to torture or other cruel, inhuman or degrading treatment or punishment.

It should be noted that this interpretation depends on what one considers capital punishment to be. If we are to consider the death penalty as torture or inhuman treatment, then it is not only in violation of the Rights of the Child, but it is also in violation of the **Universal Declaration of Human Rights**, which explicitly dictates under Article 5 that “no person shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment”.<sup>8</sup>

Nevertheless, the Universal Declaration of Human Rights is non-binding. Countries are not internationally mandated to abide by the provisions of this declaration.

In fact, the Iranian Penal Code in many ways is abiding by the tenets of human rights. In relation to juvenile crimes for example, children who commit crimes are not immediately subject to execution or the death penalty; rather, they are sentenced to

2 WMA International Code of Medical Ethics, 2006. Retrieved from <https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/> on August 17, 2018.

3 WMA Council Resolution on the Relation of Law and Ethics, 2003. Retrieved from <https://www.wma.net/policies-post/wma-council-resolution-on-the-relation-of-law-and-ethics/> on August 17, 2018.

4 Iran: Teenager’s execution exposes complicity of courts, parliament and doctors in assault on children’s rights. Amnesty International Public Statement, 29 June 2018. Retrieved from <https://www.amnesty.org/download/Documents/MDE1386962018ENGLISH.PDF> on August 17, 2018.

5 Ibid.

6 International Covenant on Civil and Political Rights, 1966. Office of the High Commissioner of Human Rights, United Nations. Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/ccpr.aspx> August 17, 2018.

7 Convention on the Rights of the Child, 1990. Office of the High Commissioner for Human Rights, United Nations. Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx> on August 17, 2018.

8 The Universal Declaration of Human Rights, 1948. United Nations General Assembly. [http://www.un.org/en/ga/search/view\\_doc.asp?symbol=A/RES/217\(III\)](http://www.un.org/en/ga/search/view_doc.asp?symbol=A/RES/217(III)).

correctional and rehabilitation measures.<sup>9</sup> However, the age of criminal responsibility for a child is associated with age of mental maturity or puberty under Shari'a Law (and consequently the Iranian Penal Code), which is around 9 years of age for girls and 15 years for boys. A judge must therefore decide a juvenile's sentence based on whether the child was mentally mature at the time the crime was committed. This maturity assessment is made by physicians of the Legal Medicine Organization of Iran.

Physician contribution to this decision by providing a medical opinion is effectively facilitating the execution of individuals and consequently violating international human rights law and their ethical duties as physicians. As stated in the **WMA Resolution on Physician Participation in Capital Punishment**<sup>10</sup>, it is unethical for physicians to participate in capital punishment, in any way, or during any step of the execution process.

The World Medical Association, as a representative of physicians worldwide, has continuously published Resolutions and Declarations pertaining to physician involvement in capital punishment.

In 1975, the **WMA Declaration of Tokyo**<sup>11</sup> defined torture as the deliberate,

systematic, or wanton infliction of suffering by one or more persons acting alone or on the orders of any authority. It called on National Medical Associations to encourage physicians to continue their professional development training and education in human rights.

In 1997, the **WMA Declaration of Hamburg**<sup>12</sup> encouraged its constituent members to take action so that physicians are held accountable before the law in case of complicity in acts of torture, and to protest internationally against any pressure to involve physicians in acts of torture.

Following global reports in 2009 regarding practices by health professionals indicating their direct involvement in the infliction or ill-treatment and participation in interrogation processes, the WMA published the **Council Resolution on Prohibition of Physician Participation in Torture**<sup>13</sup>.

Inhuman or Degrading Treatment or Punishment in Relation to Detention and Imprisonment, 2016. World Medical Association. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-tokyo-guidelines-for-physicians-concerning-torture-and-other-cruel-inhuman-or-degrading-treatment-or-punishment-in-relation-to-detention-and-imprisonment/> August 17, 2018.

12 WMA Declaration of Hamburg Concerning Support for Medical Doctors Refusing to Participate in, or to Condone, the use of Torture and other Cruel, Inhuman or Degrading Treatment, 2017. World Medical Association. Retrieved from <https://www.wma.net/policies-post/wma-declaration-of-hamburg-concerning-support-for-medical-doctors-refusing-to-participate-in-or-to-condone-the-use-of-torture-or-other-forms-of-cruel-inhuman-or-degrading-treatment/> August 17, 2018.

13 WMA Council Resolution on Prohibition of Physician Participation in Torture, 2009. World Medical Association. Retrieved from <https://www.wma.net/policies-post/wma-council-resolution-on-prohibition-of-physician-participation-in-torture/> August 17, 2018.

Although the WMA cannot hold its national medical association members responsible for the actions, policies, and laws of their respective governments, the WMA released a **Statement on the United Nations Resolution**<sup>14</sup> in 2013 recommending and supporting the UN GA Resolution 65/206 calling for a moratorium on the use of the death penalty.

However, National Medical Associations must also work towards guaranteeing that physicians are complying with the fundamental principles of medical ethics by prohibiting physician involvement in the preparation, facilitation, or participation in executions of persons who commit crimes as juveniles.

Moving forward, the international community of physicians and medical professionals must continue to collectively call upon their Iranian colleagues and their organizations to acknowledge a physician's duty to do no harm. The medical maturity assessments as described in this article and as provided by the Legal Medicine Organization of Iran, whereby physicians are using their medical knowledge to violate ethical duties, human rights, and civil liberties, are both: unethical and illegal.

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14 WMA Statement on the United Nations Resolution for a Moratorium on the Use of the Death Penalty, 2013. World Medical Association. Retrieved from <https://www.wma.net/policies-post/wma-statement-on-the-united-nations-resolution-for-a-moratorium-on-the-use-of-the-death-penalty/> August 17, 2018.

9 Islamic Penal Code of the Islamic Republic of Iran – Book Five, 2013. Iran Human Rights Documentation Center. Retrieved from <http://www.iranhrdc.org/english/human-rights-documents/iranian-codes/1000000351-islamic-penal-code-of-the-islamic-republic-of-iran-book-five.html> on August 17, 2018.

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## Euthanasia in Canada: a Cautionary Tale



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We are Canadian physicians who are dismayed and concerned by the impact – on patients, on doctors, on medical practice – of the universal implementation, in our country, of euthanasia defined as medical “care” to which all citizens are entitled (subject to the satisfaction of ambiguous and arbitrary qualifying criteria). Many of us feel so strongly about the difficulty of practicing under newly prescribed constraints that we may be forced, for reasons of personal integrity and professional conscience, to emigrate or to withdraw from practice altogether. All of us are deeply worried about the future of medicine in Canada. We believe this transformation will not only be detrimental to patient safety, but also damaging to that all-important perception by the public – and by physicians themselves – that we are truly a profession dedicated to healing alone. Thus, we are alarmed by attempts to convince the World Medical Association (WMA) to change its policies against physician participation in euthanasia and assisted suicide.

Notwithstanding the disavowals of those promoting change of the WMA policies, such a change would encourage legalization of the procedures in other countries, and it is certain that this would have a major adverse impact on our patients and colleagues around the world. Hence, we believe it is important for them to reflect upon our perspective: that of Canadian physicians who refuse to kill our patients or to help them

commit suicide, who refuse to facilitate euthanasia or assisted suicide by others, and who practise in a country where such refusals are widely thought to reflect unacceptably extreme and unprofessional views. Our perspective has been missing in WMA discussions until now.

### The Law

In Canada, the federal government is responsible for criminal law and the provinces have jurisdiction over health care and enforcement of criminal law. In 2014, the Province of Quebec exploited this constitutional arrangement by legally redefining end-of-life medical care to include euthanasia [1]. The law came into force in December 2015.

In February 2015, the Supreme Court of Canada ruled in *Carter v. Canada* that physicians may provide euthanasia or assisted suicide for competent adults who clearly consent, who have a grievous and irremediable medical condition (including illness, disease, or disability) that causes enduring and intolerable physical or psychological suffering, and that cannot be relieved by means acceptable to the individual [2]. The criteria are broader than those specified in the Quebec statute.

The Criminal Code was amended in June 2016 to give effect to the ruling throughout

the country [3]. Quebec law allows only euthanasia, and only for someone “at the end of life” who is in an “advanced state of irreversible decline in capability” [1]. Similarly, the Criminal Code states that the natural death of the candidate must be “reasonably foreseeable” (an undefined term) and replicates Quebec’s requirement of an advanced state of decline. It also specifies that the candidate’s illness, disease or disability be incurable [3].

Determined patients who do not meet these requirements because of natural disease processes can opt to starve themselves to the point of qualifying for the procedures [4]. This has been denounced as “cruel” and suggested as a reason to abolish the requirements [5]. Lawsuits underway in British Columbia [6] and Quebec [7] assert the requirements are unconstitutional.

### Expanding Access to Euthanasia and Assisted Suicide

If current lawsuits are successful, euthanasia and assisted suicide will be available as a supposed “treatment” for mental illness, since not all mental illnesses permanently impair decisional capacity. Moreover, the Supreme Court did not rule out allowing euthanasia and assisted suicide for reasons beyond those identified in *Carter* [2].

Within a year of the ruling, the pressure for “Carter Plus” had become so great that the federal government legally committed itself to consider allowing euthanasia and assisted suicide for adolescents and children, for indications caused by mental illness alone, and by advance directive (for those who lack capacity, like patients with dementia) [8].

In sum, while the WMA regional meetings demonstrate there is no appetite for euthanasia outside some parts of Europe and the European diaspora, in Canada we have observed that even the prospect of legalization whets the appetite for it, and the appetite is not satisfied by legalization alone.

## The unreliability of Legal “Safeguards”

The Supreme Court of Canada believed that “a carefully designed and monitored system of safeguards” would limit risks associated with allowing physicians to kill patients or help them commit suicide [2]. However, the Vulnerable Persons Standard, developed to assist in establishing such safeguards, finds current Canadian law seriously deficient [9]. Even supplemented by provincial and professional guidelines, current criteria are so broad as to have permitted lethal injection of an elderly couple who preferred to die together by euthanasia rather than at different times by natural causes [10].

Despite this, only a year after legalization, Canadian Euthanasia and Assisted Suicide (EAS) practitioners were already complaining about having to meet with patients (perhaps more than once), review their often “lengthy and complicated” medical histories, counsel and overcome resistance from family members [11], refer patients to psychiatrists or social workers [12], find two independent witnesses to verify the voluntariness of a patient’s request [13], and manage the “paperwork and bureaucracy involved,” [14] such as having to com-

plete forms and fax reports to the coroner [13;15]. What others see as safeguards, they characterized as “disincentives” to physician participation that were creating “barriers” to access.

## Demand for Collaboration

EAS practitioners also claimed that there was “a crisis” because so few physicians were willing to provide euthanasia or assisted suicide [16]. Their alarm seems to have been triggered by a 46.8% increase in EAS deaths in the second half of the first year of legalization. Canada’s EAS death rate in the first year – about 0.9% of all deaths [17] – was not reached by Belgium for seven to eight years [18].

However, inter-jurisdictional comparisons indicate that, even in the first year of legalization, more than enough Canadian EAS practitioners were available to meet the demand [19]. This ought to make coercion of unwilling physicians unnecessary, but prominent, influential and powerful people in Canada disagree.

It is true that nothing in the Criminal Code requires physicians to personally kill patients or help them commit suicide [3]. However, nothing in the Criminal Code prevents compulsion by other laws or policies. Thus, for example, Canada’s largest medical regulator demands that physicians who are unwilling to personally provide euthanasia or assisted suicide must collaborate in homicide and suicide by referring patients to colleagues who are willing to do so [20].

We categorically refuse. Such collaboration would make us morally responsible for killing our patients; if not for the *Carter* decision, it would make us criminally responsible and liable to conviction for murder, just as it still does in most parts of the world. For refusing to collaborate in killing our patients, many of us now risk discipline

and expulsion from the medical profession. How has this come about?

## Access to Euthanasia and Assisted Suicide as Entitlements

Part of the explanation is that Canada’s state-run health insurance system pays for “medically necessary hospital and physician services” from public funds. Most Canadian physicians are independent contractors paid only for services we provide, but many Canadians now believe we are state employees, and we face an entrenched attitude of entitlement. Since taxpayers pay for “medically necessary” health services, many people think it is unacceptable for physicians to refuse to provide those [21].

And what counts as a “medically necessary” service? In brief, anything declared to be so by the state. As we have seen, in 2014 the Quebec government redefined medical practice to include euthanasia. Indeed, Quebec deliberately restricted the practice of euthanasia to physicians [1].

## Access to Euthanasia and Assisted Suicide as Human Rights

The sponsor of Quebec’s law claimed that euthanasia would remain “very exceptional” [24]. However, the law also said qualified patients had a right to euthanasia, and the exercise of a right cannot be exceptional. Thus, all public health care institutions (residences, long term care facilities, community health centres and hospitals – including palliative care units) are required to provide or arrange for euthanasia [1]. Even this, however, has not been enough.

McGill University Health Centre complied with Quebec law by arranging to transfer patients from the palliative care unit to be lethally injected elsewhere in the facility.

The Quebec Minister of Health forced euthanasia into the palliative care unit, citing “patients’ lawful right to receive end-of-life care” [23; 24].

Quebec law allows hospices to opt out of providing euthanasia [1], but when Quebec hospices opted out, the Minister of Health denounced them for “administrative fundamentalism,” declaring their refusal “incomprehensible.” Notwithstanding the law, a prominent Quebec lawyer urged that their public subsidies be withdrawn, accused them of compromising the right of access to care, and warned that allowing refusal was a slippery slope [25]. A similar situation is also being faced by the hospices in other provinces such as British Columbia [26].

Quebec physicians and health care practitioners now work in environments characterized by an emphasis on a purported ‘right’ to euthanasia. The notion that access to euthanasia and assisted suicide is a fundamental human right has spread across Canada since the Supreme Court of Canada ruling in *Carter*. We are accused of violating human rights – even called bigots – because we refuse to kill or collaborate in killing our patients [27].

## Providing Euthanasia as an Ethical/Professional Obligation

Leaders of the medical profession contributed substantially to the legal redefinition of euthanasia as a medical act and to the legalization of physician assisted suicide and euthanasia.

The Collège des médecins du Québec (CMQ) told Quebec legislators that actively causing the death of a patient is “a medical procedure” for which physicians must be completely responsible, insisting that physician assume “the moral burden” of killing patients [28]. The Federation of General Practitioners of Quebec was ada-

mant that only physicians should provide euthanasia [29].

The Canadian Medical Association (CMA) secured approval of an apparently neutral resolution on euthanasia and assisted suicide, supporting both physicians willing to provide the services and those unwilling to do so [30]. The CMA later told the Supreme Court of Canada those positions for and against physician participation in euthanasia/assisted suicide were both ethically defensible, and that its long-standing policy against physician participation would be revised to reflect support for both views [31].

However, in 2014, prior to the 2015 Supreme Court ruling its legalization, the CMA formally approved physician assisted suicide and euthanasia (subject to legal constraints) as responses to “the suffering of persons with incurable diseases.” It classified both practices as “end of life care,” and promised to ensure access to “the full spectrum” of end of life care (i.e., including euthanasia and assisted suicide) [32]. The Supreme Court cited the CMA’s new policy when it struck down the law two months later [2].

By redefining euthanasia and assisted suicide as therapeutic medical services [33], the CMA made physician participation normative for the medical profession; refusing to provide them in the circumstances set out by law became an exception requiring justification or excuse. That is why public discourse in Canada has since centred largely on whether or under what circumstances physicians and institutions should be allowed to refuse to provide or collaborate in homicide and suicide: hence the “long debate” about conscientious objection at the CMA’s 2015 annual meeting to which the CMA Vice-President, Medical Professionalism referred in his World Medical Journal article [34].

The CMA Vice-President, Medical Professionalism elsewhere noted that, for years,

physicians opposed to euthanasia and assisted suicide have lobbied the CMA to support their right to refuse to participate in the procedures. “They have made tearful pleas at several CMA General Council meetings, asking their non-objecting colleagues to support them and to defend their rights” [35]. We have had to do this precisely because of the reversal of CMA policy against physician participation in euthanizing patients, the reclassification of euthanasia and assisted suicide as medical services, and the insistence that there should be no “undue delay” in providing them [36].

To be fair, our pleading has not been in vain. The CMA does support physicians who refuse to provide or refer for euthanasia and assisted suicide, asserts that the state should develop mechanisms to allow patients direct access to the services without violating physicians’ moral commitments, and rejects discrimination against objecting practitioners [36]. But this advice can be ignored and, when it is, Hippocratic practitioners face the state in court and foot the bill for expensive constitutional challenges [37]. Further, public calls from influential voices have been heard for those medical students who are personally opposed to the euthanasia imperative, to either abandon, or refrain from applying for, medical training [38].

## Canada’s Euthanasia/Assisted Suicide Regime

The CMA is sincerely convinced that it “did the right thing” in shaping the debate and law in Canada and that it is on the right side of history. It is urging the WMA to follow its lead [34]. Our colleagues in other countries thus need to be aware that the EAS regime in Canada is one of the most radical in the world.

Patients do not have a ‘right to euthanasia’ in the Netherlands [39] or in Belgium [40], though long practice inclines the public to the contrary view [41]. Euthanasia is not

permitted in either country unless a physician is personally convinced there is no reasonable alternative [42; 43]. Similarly, Dutch and Belgian physicians must be personally convinced that a patient's suffering is intolerable and enduring [42, 43], and Belgian physicians may insist upon criteria beyond those set by law [42].

In Canada, however, access to euthanasia and assisted suicide is seen as a tax-paid entitlement, is described as a "constitutionally protected civil and human right" [44], and homicide and suicide are legally and professionally defined to be therapeutic medical services. Moreover, a physician's conviction that there are other reasonable and efficacious alternatives is irrelevant; patients can insist upon lethal injection. Finally, the criterion of intolerable suffering is entirely subjective, established unilaterally by the patient.

Small wonder, then, that the onus seems increasingly to lie on physicians to show why euthanasia should be refused, and that health care administrators may be more anxious about being accused of "obstructing access" [45] than about "killing people who really ought not to be killed" [46].

Only a year after legalization, Dr. Yves Robert, Secretary of the CMQ was alarmed by "the rapidity with which public opinion seems to have judged [the new law] insufficient."

"If anything has become apparent over the past year, it is this paradoxical discourse that calls for safeguards to avoid abuse," he wrote, "while asking the doctor to act as if there were none. ... [W]e see the emergence of pressure demanding a form of death à la carte," he warned [47].

## Patients and Palliative Care

As Hippocratic practitioners, our focus is on the good of our patients, avoiding thera-

peutic obstinacy and responding to their suffering with compassion, competence, and palliative care. We are disturbed that the number of Quebec practitioners entering palliative care dropped after legalization of euthanasia, and the CMQ and the Quebec Society for Palliative Care are concerned that patients are choosing euthanasia because adequate palliative care is unavailable [48].

We are disturbed and grieved by the story of a 25-year-old disabled woman in acute crisis in an Emergency ward, pressured to consider assisted suicide by an attending physician, who called her mother "selfish" for protecting her [49].

We are disturbed and angered to hear that hospital authorities denied a chronically ill, severely disabled patient the care he needed, suggesting euthanasia or assisted suicide instead [50].

And we were astonished to hear that some emergency physicians in Quebec were, for a time, letting suicide victims die even though they could have saved their lives. The incidents came to light at about the time the Quebec euthanasia law came into force, and the president of the Association of Quebec Emergency Physicians speculated that the law and accompanying publicity may have 'confused' the physicians about their role [51].

These incidents are entirely consistent with the acceptance of euthanasia and physician assisted suicide and they illustrate grave violations of traditional medical ethics. This is not coincidental.

## Euthanasia and the Transformation of Medical Culture

Canadian medical leaders learned that, in other jurisdictions, legalizing assisted sui-

cide and euthanasia caused "changes in the medical culture" leading to "general, overall comfort" with the law [52].

However, when emergency physicians refuse to resuscitate patients who attempt suicide and urge disabled patients in crisis to request euthanasia, such "changes in the medical culture" are not, in our view, consistent with ensuring patient safety, nor with maintaining the trust essential to preserving the Hippocratic physician-patient relationship.

And when physicians are told to write 'natural death' instead of 'euthanasia' on the death certificates [53,54] – and, by extension, to misrepresent facts – "changes in the medical culture" may make physicians comfortable, but we do not believe that they will sustain trust in the medical profession. Even newly released federal guidelines for monitoring euthanasia lack any emphasis on prevention of EAS, in favour of merely regulating these practices [55; 56; 57].

Finally, when a Jewish nursing home forbids euthanasia and assisted suicide on its premises out of respect for Jewish beliefs and concern for its residents (who include Holocaust survivors), "changes in the medical culture" may encourage applause for the EAS practitioner who crept in at night to lethally inject someone [58], but we do not applaud; we are aghast.

Our observations and personal experiences over the last two years confirm our belief that the practice of Hippocratic medicine is fundamentally incompatible with euthanasia and assisted suicide. Mandating system-wide provision and physician involvement in the practices can be expected to transform medical culture, ultimately making Hippocratic medical practice impossible.

The WMA regional conferences demonstrate that the great majority of physicians worldwide agree with us. Nonetheless, it is true that some physicians and patients seek

euthanasia or assisted suicide where the procedures are legal. Supposing that killing people or helping them to commit suicide might sometimes be an acceptable response to human suffering (something we do not concede), how might these demands be accommodated?

The answer is intuitively obvious: with the least possible disruption of existing long-standing medical practice. And from this perspective a completely non-medical solution would be best. Where this is no longer practicable, law and policy should allow medical practice to remain largely unchanged. Patients have no entitlement; practitioners and institutions have no duty; medical associations respectfully continue unresolved ethical debates; the amplitude of the phenomena remains proportional to minority demands. The introduction of euthanasia in Canada has caused doubt, conflict and crisis. In our view, new disciplines, new professions and new methods may arise to satisfy new social goals; but not in the name of Medicine. We believe that doctors, and medical associations, should vigorously defend the successful model inherited from our past. Euthanasia is not medicine.

As Canadians, we are saddened by this situation, but we hope that our experience and observations will serve as a warning for our colleagues in other countries, and their patients. Most important: The World Medical Association must recognize that accommodating the kind of radical change in medical culture underway in Canada is ill-advised. Mindful of the legacy of past WMA leaders, such as former Secretary General, Dr. Andre Wynen, who, based on his personal experience, stood courageously against any minimization of the dangers of euthanasia to patients and physicians [59], we advise against any compromising additions or modifications to existing WMA declarations, and strongly support a full defence of established policy against euthanasia and assisted suicide.

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## Telemedicine and its Ethical Aspects



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Telemedicine entered the scene during the early 19th century and has been steadily growing and further developing in the background. Dr Hugo Gernsback featured his 'teledactyl' device in the 1925 edition of the Science and Invention Magazine, with the hope that the device would be a medical breakthrough whereby physicians would be able to examine patients from a distance using radio technology. This 'failed' invention paved the way for telemedicine, and was shortly followed by studies at the University of Nebraska in 1959 where physicians were able to transmit neurological examinations to medical students across the campus via a two-way interactive television. Within ten years, physicians were able to use a telemedicine link to provide health services at a Norfolk State Hospital over a distance of 180 kilometres [1].

In general, telemedicine is defined as the remote diagnosis and treatment of patients via telecommunications technology. The World Medical Association (WMA) describes telemedicine as "the practice of medicine over a distance, in which inter-

ventions, diagnostic and treatment decisions and recommendations are based on data, documents and other information transmitted through telecommunication systems" [2]. Telemedicine can refer to consultation between a physician and a patient or between two physicians/health professionals, with a primary physician/health professional being in the same location as the patient. Telehealth services may be provided through two types of communication platforms: (i) asynchronous communications, which is known more commonly as "store and forward" (e.g. X-rays, CT scan reports, video-recorded symptoms) and (ii) synchronous communication, described as "real-time" communication (e.g. video consultation) [3].

The definition of telemedicine can differ across different jurisdictions, and what is legal in one jurisdiction may be illegal in the other. Some jurisdictions recognise telemedicine as an interaction between the physicians and their patients and some jurisdictions limit telemedicine between health professionals [4]. It is therefore important for physicians to understand

definitions of telemedicine in their jurisdictions" [5].

Top fields in telemedicine include Tele-radiology, Telepathology, Teledermatology, Telepsychiatry, Teleophthalmology, Telenephrology, Teleobstetrics, Teleoncology, and Telerehabilitation, Telesurgery and telemonitoring (or remote surgery). Telemedicine can also be used for patient education and follow-up [5-7].

### Benefits of Telemedicine

Telemedicine can be used to improve access to healthcare services in remote and underserved areas. [8] Telemedicine can be used as a direct link to patients or to enable remote facilities to obtain specialised support from major centres [8, 9]. Telemedicine can also be used for learning and development of junior physicians, resident officers, nurses and general practitioners. Increasingly, telemedicine is being used for patients with barriers to access outside geographical limitations; these include physical disability, employment, family commitments (including caring for others), patients' cost and physician schedules.

Telemedicine can allow for frequent follow-up of chronic patients, therefore, increasing contact time at low costs. Patient tele-education also assists in providing patients with individualised health promotion messages and may improve empowerment [9].

### Potential Risks in Telemedicine

**Quality of care:** The ultimate purpose of any medical care is to maintain or improve health and well-being. Like all clinical interventions, telemedicine should be subjected to the evaluation of efficiency, effectiveness and cost-effectiveness. Arguments in favour of the use and expansion of telemedicine include, amongst others,

increased access and affordability. This should, however, not be done at the expense of quality of care, and in fact should not replace access to essential clinical services and face-to-face consultations, as not all clinical conditions can be treated using telemedicine.

Telemedicine can result in three types of quality problems: [10] (i) Overuse of medical care due to unnecessary consultations and investigations, (ii) under-use of medical care through failure to conduct appropriate clinical examination and referral appropriate/referral delayed referral and (iii) poor technical or interpersonal performance (e.g. incorrect interpretation of pathology specimen or inattention to patient concerns) [11]. Telemedicine should be used as an adjunct to health services and not as a standalone intervention.

The effectiveness of telemedicine: Studies of effectiveness in telemedicine are inconsistent. Compared to usual care, telemedicine did not result in the improvement in outcomes in heart failure [12, 13]. In one systematic review, telemedicine was found to be associated with decreased hospitalisation and mortality, and resulted in lower patient satisfaction<sup>12</sup>. In another randomised control trial, telemedicine was reported to reduce HBA1C but had no effect on health outcomes such as mortality [14]. The inconsistency in findings can be due to variable telemedicine platforms, settings and to the extent to which usual care is replaced or complemented by telemedicine. It is therefore, important that physicians test effectiveness, efficiency, safety and feasibility of telemedicine platforms in their setting before wide-scale rollout.

## Ethics and Telemedicine

Some of the most prominent ethical concerns include the effect on patient-physician relationships, and threats to patient

privacy[14]. Properly informed written consent requires that all necessary information regarding the telemedicine visit be explained fully to patients, including explaining how telemedicine works, how to schedule appointments, privacy concerns, the possibility of technological failure, protocols for contact during virtual visits, prescribing policies, and coordinating care with other health professionals in a clear and understandable language, without influencing the patient's choices [15].

Telemedicine involves the use of an information technology platform, which can result in unintended confidentiality breaches by hacking and unauthorised access. IT staff responsible for telemedicine platforms may not have similar ethical rules as the medical professionals. This risk is even higher when secular telemedicine platforms such as Skype or WhatsApp are used. Therefore, a physician needs to use appropriate, accredited, secure and compliant IT platforms for telecommunication where applicable.

Generally, the patient needs to have an existing relationship with the medical professional performing the telemedicine consultation. There is a therapeutic value of face-to-face encounters with a physician that helps to build a relationship of mutual trust and rapport building[16]. Face-to-face consultation allows the physician to obtain an appropriate history as well as conduct general and symptomatic examinations. For these reasons, telemedicine should only be implemented for existing patients, where the physician has an intimate knowledge of the patient's history.

In providing telemedicine, physicians must be aware of its benefits and harms. Telemedicine should not replace face-to-face consultation. There are circumstances where telemedicine is inappropriate and physicians must, therefore, retain their autonomy in deciding on the appropriate use of telemedicine. The standards of care provided in

telemedicine should be similar to face-to-face consultations.

Telemedicine can be harmful as the physicians' ability to clinically examine the patients is limited. Physician-only relies on two (visual and audio) senses instead of four (visual, audio, smell and touch) to complete a clinical exam.

**Justice:** The healthcare system has a duty to distribute social benefits and burdens equally. Telemedicine can widen the gap in health outcomes if people are treated differently based on their ability to access telecommunication or denial of necessary face-to-face consultation in lieu of telemedicine.

Furthermore, reimbursement for telemedicine should be proportionate to the burdens. Physicians should be careful of perverse incentives geared to promote uptake of telemedicine as this can erode the ethics in medicine [15, 17].

## Barriers to Implementation of Telemedicine

Infrastructure remains a huge barrier to expansion and access to telemedicine. Ironically, this affects remote and rural societies who are believed to be beneficiaries of telemedicine. Instead, telemedicine is expanding rapidly in urban areas and metropolises. Barriers that physicians, in general, experience with the implementation of telemedicine in their practices include a lack of access to infrastructure, requirements of complex systems, absences of standards in telemedicine, and a lack of direction from regulatory bodies and national departments of health [8].

## Legal Considerations

The regulations for telemedicine vary from country to country and within countries. Generally, there is also a lack of harmony

within and between countries legal frameworks. For, examples, in the US, physicians are required to be licensed or registered with the relevant regulator to practise telemedicine. However, regulators in other countries are often silent on consultations across jurisdictions [18]. This can threaten a patient's safety and lead to abuse by unscrupulous fraudsters. Physicians should be cognisant that in the absence of guidance on cross-jurisdictional regulations, long-arm laws may grant the court's jurisdiction over out-of-state individuals.

Whilst there are telecommunication laws, telemedicine requires a special type of regulation due to the sensitivity of medical information, and the requirements for regulation of physicians and medical interventions. This requires harmonisation of both medical and telecommunication legal frameworks.

Telemedicine can increase the potential for litigation due to an inability to assess symptoms and signs appropriately through electronic consultation media.

## Conclusion

Telemedicine can provide access to health-care in under-resourced areas. However, physicians must adhere to biomedical ethics and be cognisant of the unintended adverse effects both at individual and population level. Face-to-face medicine remains the gold standard of care. Telemedicine should not be used for any medical emergencies (unless justified by lack of access) or conditions where physical examination is required.

Physicians should use their professional judgment, along with available legislation and guidelines, to decide when telemedicine is appropriate. Prescribing medicine virtually is generally acceptable; however, physicians should only prescribe medicine when there is a pre-existing relationship with the patient and guard against potential abuse and fraudulent use of prescribed medicine. Physicians need to be aware of medicines that cannot be prescribed via telemedicine consultations. Physicians should only practise telemedicine in countries or jurisdictions where they are licenced to practice. Cross-jurisdictional consultations should only be allowed between two physicians.

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## Global Migration and the Health Workforce: the Experiences of Internationally Educated Health Professionals



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Migration has been a constant of human life for centuries [1]. In our own time, the movement of individuals between cities, countries, and cultures has accelerated due to ease of transportation and communication, yet the fundamental issues faced by people uprooting themselves and their families for new opportunities remain similar [2]. Issues related to the alignment of expectations with realities, integration in new communities, cultural understanding within new societies, and a psychological sense of loss are all common experiences that continue to occur [3]. More recently, especially within many Western countries, increased scrutiny on migrants and migration policies have created new challenges for individuals who may simply want a better life for their families [4].

Internationally educated health professionals (IEHPs) are generally defined as indi-

viduals who received their primary education and training in a health care field in a different country than the one they currently reside within. In some cases (for example the movement of physicians between Australia and New Zealand) [2] there may be minimal regulatory, cultural, or social barriers to professional practice. In other cases (for example the movement of nurses between sub-Saharan Africa and the United States) there may be significant barriers and obstacles to overcome [3].

While political debate around migration and its benefits continues to swirl, the undeniable reality in many Western countries is that reliance upon IEHPs to complement the domestic workforce continues to increase [4, 5]. In some professions and in some jurisdictions, this reliance can be significant; for example, in the Canadian province of Ontario, upwards of 50% of all pharmacists registered to practice each year come from outside Canada or the United States, and without their contributions to the workforce, the practice of the pharmacy profession in Ontario would be overwhelmed [6].

Despite increasing reliance on IEHPs for an aging population and health care systems under stress, relatively little is known about their experiences in navigating the personal and professional transitions required by all migrants [6]. In our current time in which migration in general has become a political issue, and actions to reduce all forms of migration currently seize the public agenda, policy makers may lack an understanding of the real, important, and invaluable contributions made by

IEHPs in allowing health care systems to continue to function safely and effectively [7].

These contributions, however important, must also be balanced against perceptions related to integration of newcomers into the social and cultural fabric of their adopted societies. Integration of IEHPs into the community and into the health care system may be more complicated today due to the patterns of migration, particularly the movement of peoples across large geographic – and cultural – distances. Well-publicized cases of (for example) foreign-trained physicians refusing service to gay and lesbian patients due to religious differences can sometimes create the impression for the public – and for policy makers – that IEHPs are more bothersome than helpful. The reality, of course, is that in many Western countries, reliance on IEHPs to complement the domestic workforce will only increase over time [1, 4, 6].

Given this reality, it is important to understand the experiences and diverse trajectories of IEHPs as they become a more important part of our communities and health care systems for several reasons. First, it is imperative that policy makers understand both the value IEHPs bring to domestic health care systems as well as the barriers and facilitators to fuller integration in the workforce [5]. Second, regulators need greater clarity around how their policies and practices may create inadvertent access barriers that ultimately may result in unfairness to potential registrants or inefficiencies that adversely impact patient care by inappropriately reducing the number of health care providers available. Third, public awareness of the contributions of, and struggles faced by, IEHPs is essential: while health care personnel shortages are an issue across the globe, few members of the public understand the importance of global migration as a health human resources planning tool to forestall staffing problems. Fourth,

educators and those involved in skills upgrading and immigration settlement require further research to support their curricular efforts to enhance professional and community integration of IEHPs as efficiently and effectively as possible. Finally, IEHPs themselves need access to better information about the personal and professional implications of migration; in cases of economic or voluntary migration, IEHPs may have unfounded or unrealistic expectations regarding the ease and speed with which their qualifications may be recognized and respected in their adopted country of choice [6].

## Healthforce Integration Research and Education for Internationally Educated Health Professionals (HIRE IEHPs)

From 2012–2017, the Canadian government (like many national governments) recognized the importance of greater understanding of the experiences of IEHPs in Canada, especially given the large and growing reliance of the Canadian health care system for foreign-trained doctors, nurses, pharmacists, and other health professionals [6]. As part of a menu of initiatives designed to address needs of multiple stakeholders across the country, the HIRE IEHPs initiative was funded to support integration of IEHPs in the Canadian health workforce. The ultimate objective was to use research to guide curriculum design for educators and to provide supports for employers and community agencies to more effectively and efficiently support full integration of IEHPs into Canadian health care practices and settings.

Over the course of this project, several key insights have emerged, which may be of relevance to jurisdictions similar to Canada working to support and enhance integration

of IEHPs to alleviate domestic health care workforce shortages:

### 1. Personal and Professional Migration Needs Differ

During the course of the project, we worked with literally thousands of foreign trained health professionals from all over the world, representing over a dozen regulated and recognized health professions including medicine, dentistry, midwifery, nursing, and pharmacy. Across these interactions – and regardless of profession, country of origin, gender, or age – a strikingly common theme emerged amongst voluntary/economic migrants to Canada. Almost without exception, health professionals who decided to leave “home” and move to Canada did so with the express purpose of enhancing prospects and improving life for their children, rather than for themselves [6]. In some cases, this same sentiment was expressed by IEHPs even if they were currently childless. IEHPs recognized that “back home” they had social status, good jobs, good incomes, and a reasonable or good quality of life – but that they expected that migration to Canada would be of primary benefit for their children rather than for themselves. Their professional degree/designation was merely of instrumental use to meet Canada’s immigration requirements; virtually no IEHPs in our project said they had undertaken the stressful migration process to Canada because of professional opportunities or the chance to practice their profession. Indeed, the vast majority described how they would personally be less well-off, less professionally satisfied, and less personally happy because of the migration experience but in the longer term it would be a sacrifice that was rewarded by the happiness and future prosperity of their children [8].

This is a crucial insight for regulators, educators, and employers: professional satisfaction and practice are secondary to

parental responsibilities for the vast majority of IEHPs, yet the existing literature on IEHPs rarely discusses this issue. It is easy to overlook the reality that health professionals are also people who must juggle multiple roles and multiple responsibilities; for the IEHPs in this project, their professional integration was merely a tool to support personal/social integration to support their children. This underlying motivation was frequently ignored or overlooked throughout their registration and employment experiences yet it is crucial to understanding who they were as individuals. Perhaps most importantly when viewed from this perspective, failure to become licensed as a professional or delays in finding suitable employment are not simply “personal” issues – they have enormous implications for a family network, a sense of self-worth and self-identity, and can therefore provoke strong emotional responses.

### 2. Domestic professional and regulatory cultures can appear cold and indifferent to outsiders

A second common theme across all professions was the interactions experienced with profession-specific regulators, educators, professional associations, and employers. IEHPs in this project spoke of the difficulties they had simply understanding what they needed to do in order to get registered and gain employment. Bureaucratic indifference or complexity was frequently experienced as hostility or discrimination due to country of origin. While very few IEHPs in this project reported blatant racism or outright discrimination, a subtle level of systemic barriers was omnipresent, blocking progress through the licensing system and frustrating attempts at gaining Canadian experience or employment. This was interpreted as the system being “rigged” to favour Canadian graduates over non-Canadian graduates; while most

IEHPs did not necessarily object to this type of favouritism per se, they did object to the lack of transparency and clarity about what they needed to do in order to continue to progress in the system. While official policy and practice amongst regulators, educators, and employers in Canada clearly emphasizes non-discrimination and treating all applicants fairly regardless of country of origin, the lived experiences of many IEHPs suggest improvements are needed in systems to achieve this policy objective.

### 3. Technical/procedural skills are less important than social/contextual ones

Many IEHPs – regardless of their professional background – expressed surprise at the extent to which the Canadian health care system prioritized social competencies over technical competencies, particularly in fields such as medicine. In most cases, IEHPs were expecting greater challenges in mastering the technical nuances of Canadian health practice than they experienced; indeed many project participants noted that the actual practice of their profession from a technical perspective was not that dissimilar in Canada to their experience in another country. What was completely different – and in many cases very overwhelming – were the multiple social interactions and interpersonal niceties that characterize professional practice in Canada. The conversational burden amongst health care professionals, and the “small talk” demanded by patients was frequently challenging for IEHPs to master, which in turn may have led Canadian patients and providers to label IEHPs as “cold”, “aloof” or “not personable enough to work here”. Most IEHPs reported managing to pass requirements related to the technical aspects of their professional work (e.g. licensing exams), but struggling to master the application of this learning in a Canadian health care context. The impli-

cations for Canadian regulators, educators, and employers are significant – greater support for “soft skills” upgrading and training is needed to more fully engage IEHPs and help them better integrate in the Canadian system.

### 4. Communication is more than just language skills

In all regulated health professions in Canada, there are mandatory English or French language fluency requirements that must be demonstrated prior to registration in the field. Standardized widely available international tests such as the TOEFL or IELTS are used by regulators, educators, and employers to establish communication readiness for practice. IEHPs in this project were virtually unanimous in describing how passing standardized language tests was not the same as being able to communicate in a Canadian context. First, standardized language tests are frequently general in nature, and do not focus on complex medical terminology or nuances. Second, while the vast majority of IEHPs coming to Canada speak some English or French, there are many different kinds of “englishes” and “frenches” spoken in different parts of the world. Specific local idioms or dialects are rarely tested in standardized tests, yet are crucial for establishing social bonds with patients or other health care professionals. Third, standardized language tests only test verbal, written, or aural communication and as noted by many IEHPs in this project much of “communication” in health care is non-verbal in nature. Many non-verbal cues and gestures (for example, eye contact, handshakes, physical distance while speaking) are just as (if not more) important than the specific word choices and verbal communication used, yet for some IEHPs their non-verbal communication patterns were misinterpreted or misunderstood by others in a negative way. Educators, regulators and employers need to be aware that communication is not

simply about verbal skills, but instead cover a constellation of issues for which further education and support may be required to truly support integration of IEHPs in the workforce.

### 5. Patient Centeredness

The Canadian health care system – like the system of many other countries – is based upon the notion of patient autonomy, patient rights and patient centeredness. The central role of patients in decision making is instilled in health professional students from the first day of their studies. Interestingly, IEHPs in this project highlighted how their interpretations and understandings of patient centeredness were at times misaligned with Canadian expectations, particularly with respect to the patient’s role in clinical decision making. While many IEHPs in this project recognized and acknowledged that their views of patient centeredness may appear patriarchal or professionally-focused by Canadian standards, they equally expressed discomfort regarding how a truly patient-centred health care system could actually function. Many of them noted that by definition there is knowledge and skills gap between most patients and most professionals and that one of the primary responsibilities of professionals was sometimes to leverage their higher levels of knowledge in positive ways to overcome patients’ misapprehensions. While at times this may give the appearance of being overly directive or paternalistic in care delivery, many IEHPs – and in particular physicians – struggled with the overly idealistic notion of a patient-centred health care model that did not suitably value their privileged knowledge base and skill set. Many framed it in terms of responsibility to and for the patient, even if the patient him/herself was not behaving responsibly or choosing wisely. Particularly for physicians there was significant discomfort in the notion of a patient-led care team or decision making

process that was at odds with a physician's recommendations, and a sense of helplessness in terms of how to better communicate or better negotiate in such situations. For educators, regulators, and employers, this introduces challenges and opportunities around integration. First, there is a need to provide IEHPs with both background knowledge but also advanced interpersonal and communication skills to work within the patient centred worldview that is integral to Canadian health practice. Second, there may be a need for not only greater education but more robust assessment of such competencies to ensure that those entering professional practice are well equipped to deal with the realities of working with diverse Canadian populations. Third, finding ways of honouring the personal and professional traditions of IEHPs while still meeting the expectations of Canadian patients is essential – pride in one's profession and professional role is an important part of being a professional, but of course cannot be used as an excuse for inappropriately paternalistic behaviours. Finding ways of reconciling these issues is essential to support greater integration of IEHPs in the workforce, and require collaboration from all parts of a profession.

## 6. Interprofessionalism

The delivery of health care in Canada (as in many countries) is rapidly evolving towards more highly integrated interprofessional teams where professionals with different designations can perform different non-traditional roles. For example, in many parts of Canada, pharmacists may prescribe medications or physical therapists may directly order and interpret x-rays without a physician being involved. Canadian graduates of these fields are trained for these sorts of responsibilities, but those from other countries where more traditional professional silos exist may struggle with advanced practice responsibilities. Further,

in the Canadian system, it is both expected and desired that health care professionals fully discuss and debate patient care decisions with one another as a way of ensuring best possible care. At times, this may mean questioning physicians' orders in a collaborative, non-hierarchical way. Again, in many parts of the world, medical team hierarchy may be stronger than in Canada, and non-physicians may have little experience and no comfort in questioning or disagreeing with a doctor. Models of interprofessional practice require a diverse array of skill sets related to conflict management, negotiation, interpersonal communication and other soft skills, and these were identified by many IEHPs as a significant barrier to their full integration in the health care workforce. Simply stating that health care professionals work together is very different than actually working together in practice; those IEHPs (physician and non-physician alike) who come from more traditional hierarchical health care systems found themselves struggling with the reality of interprofessional practice in Canada. For educators, regulators, and employers, it is clear that further education, in-service training, and summative and formative assessment are needed to ensure interprofessional competencies are met or exceeded to facilitate greater integration in the workforce.

While the six primary themes noted above were consistent and expressed by IEHPs regardless of their profession or demographic background, they all point to the central importance of non-technical or "soft skills" in the daily practice of any profession. The real barrier to registration, licensure, employment, and meaningful integration in the Canadian health care system does not appear to be technical or procedural skills – as reported by IEHPs in this project, the main issues are those related to interpersonal, communication, interprofessional, and socio-cultural skills that are much more challenging to teach and assess.

## Enhancing Integration of IEHPs in the Workforce

One of the outcomes of the HIRE IEHPs project was the development of a repository of online resources aimed at both IEHPs themselves and employers/regulators of IEHPs to support development of the "soft skills" that are so crucial to success in the workforce. These resources are freely available on-line at [www.hireiehps.com](http://www.hireiehps.com) and are meant to be a set of tools that can be accessed before or after migration. While the focus and context of this work is the Canadian health care system, many of the modules contained in this program will have applicability to other jurisdictions. The repository was explicitly designed to be patient focused and interprofessional in its orientation, to reinforce the structure of health care delivery and practice in Canada. Any professional – physician, nurse, midwife, physical therapist etc – who is internationally educated can access the repository and benefit from its content. The repository is rich in video and patient simulations, provides opportunities for self-assessment and formative evaluation, provides links for onward readings, and uses a variety of teaching and learning strategies to convey complex content in an engaging manner that is aligned with their learning needs.

## Conclusions

Global migration continues to be an important public policy and personal issue that affects all individuals in society. In many Western countries, reliance upon internationally educated health professionals is growing and health care systems would struggle to cope with increasing demands without the contributions and talents of IEHPs. The experience in Canada suggests that key issues related to better workplace integration for IEHPs include "soft skills"

related to interprofessionalism and patient-centred care, and those specific strategies to support learning and assessment in these soft-skills areas is necessary and valuable, and will ultimately lead to better quality care for patients.

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## Some Ethical Aspects of Aesthetic Medicine in Adolescents



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Medicine is the “science or practice of the diagnosis, treatment, and prevention of disease” [1]. Another widely accepted definition is “science and art that

deals with the maintenance of health and the prevention, alleviation or cure of diseases” [2]. Considering these two definitions of medicine, it is clear that aesthetic

medicine, as a new developing branch, has some features distinguishing it from conventional medicine.

Aesthetic medicine encompasses specialties that are aimed at improving the appearance by treating certain conditions. Traditionally, aesthetic medicine includes aesthetic dermatology, reconstructive plastic surgery and cosmetic (aesthetic) plastic surgery [3, 4]. A wide range of professionals are involved in the field of aesthetic medicine – dermatologists, plastic surgeons, medical cosmetologists. In some cases, the medical team includes psychiatrists, psychologists and dietitians. The training of different professionals on Bioethics and communication skills also differs.

According to the American Academy of Aesthetic Medicine (AAAM), the term “aesthetic medicine” includes only minimally invasive procedures and is quite different from plastic surgery, which includes face lift, breast implants, liposuction, etc [5].

In this paper, we discuss all procedures that are designed to improve the appearance, not just the minimally invasive. Conventional medicine has a thousand-year history and the conditions it treats justify its means, including violating the integrity of the human body in surgical operations [5, 6]. When a person is ill, the only purpose is to cure or at least improve the condition of the patient. In aesthetic medicine, the goal is not to restore impaired health but to improve the aesthetic appearance. However, if we refer to the broad definition of the World Health Organization (WHO), "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [7]. In this sense, cosmetic procedures are justified because they create the psycho-physical balance necessary for the healthy human being. In addition, they can significantly improve the quality of life and social well-being of the individual.

## Importance of the topic

Western cultures (also Eastern ones) idolize the perfection of the human body. This is not new in human history because the beautiful appearance is associated with good health, well-being and prosperity [8]. Never before, however, improving appearance with the contribution of medical profession has been so significant. Following literature review we have formulated the following reasons, which make the topic relevant, important and requiring increased attention by the medical community and in particular by the physicians involved in cosmetic procedures.

- Aesthetic procedures (dermatological and surgical) are becoming more and more popular as a result of media, social networks and aggressive marketing, promoting a particular appearance as attractive, desirable and accessible [9].
- The contemporary values of Western societies, focused on beauty and perfection, are a source of profits for those involved

in aesthetic medicine. According to the economy laws demand and supply are interrelated. And the orientation of the medical professionals to a purely economic benefit is in contradiction with medical ethics values.

- Improving economic, social and cultural status is a prerequisite for easier access to cosmetic procedures [10, 11].

Worldwide statistics show an increase in cosmetic procedures. According to the latest published data of *The International Society of Aesthetic Plastic Surgery* for the year 2016, 31,610 million plastic surgeries were performed worldwide, and the total increase in surgical and non-surgical cosmetic procedures in one year was 9%. The ten leading countries in cosmetic procedures are the United States, Brazil, Japan, Italy, and Mexico, where approximately 41.4% of all worldwide cosmetic procedures are performed. These are followed by Russia, India, Turkey, Germany, and France [12].

- Adolescents are a specific group that needs legal protection. The number of minors willing to undergo aesthetic intervention is also rising [9].

## Aim of the study

We set our aim to study and analyze some ethical aspects of aesthetic procedures in adolescents. To achieve the aim, we used common and private scientific methods, including a documentary method and a literature review, analysis, synthesis, and a comparative method.

## Results and discussion

First we reviewed the classification of aesthetic procedures (dermatological and surgical) to assess their relevance to adolescents and the ethical acceptability of each. Anti-aging and rejuvenating procedures are

**Table 1.** Types of aesthetic procedures and degree of ethical acceptability

Type of procedure	Procedure	Ethical acceptability
<b>Reparative plastic surgery</b>	Surgical treatment Cleft lips/ palates and other congenital malformations	Ethically acceptable at a reasonable risk
<b>Reconstructive plastic surgery</b>	In case of major injuries, burns, accidents and diseases of the face and body	Ethically acceptable at a reasonable risk
<b>Aesthetic plastic surgery</b>	Breast augmentation/reduction Otoplasty Rhinoplasty Liposuction Blefaroplasty Hymenorrhaphy	Different degrees of ethical acceptability in individual cases. <b>Increased attention:</b> general anesthesia; allergic reactions; failed surgery; dissatisfying effect; complications.
<b>Non-surgical cosmetic procedures (face and body)</b>	Botulinum Toxin Facial fillers Lip augmentation Laser for acne treatment Laser hair removal	Different degrees of ethical acceptability in individual cases. <b>Increased attention:</b> local anesthesia; allergic reactions; failed procedure; dissatisfying effect; complications.

not used by minors, thus they are not included [13].

Plastic surgery is usually divided into two categories – reconstructive and cosmetic (aesthetic) surgery. The most commonly used procedures on minors are presented by type on the following table.

Reparative and reconstructive surgery is associated with pathology or major disfigurements. As these surgeries are most commonly considered ethically acceptable, we will not put emphasis on them later in this paper.

Breast augmentation is the most common aesthetic surgical intervention that is particularly discussable in adolescents. Other frequent interventions include otoplasty, rhinoplasty, lip augmentation with fillers and laser treatments. The ethical acceptability of each procedure depends on a number of factors – the severity of the condition, patient age, the risks of intervention, etc.

## Application of the Principles of Biomedical Ethics in Aesthetic Medicine

In 1979, Beauchamp & Childress published the *Principles of Biomedical Ethics*, which are now widely accepted as the ethical basis of medical practice. The Principlism is an ethical theory, based on the four fundamental principles (autonomy, beneficence, non-maleficence, and justice), and is suitable for practical purposes. In many cases, solving ethical dilemmas is based on intuitive professional knowledge [6]. The emergence of a moral case in which there is a collision of value systems imposes a higher level of rules and guidelines to be invoked by medical professionals. Ethical principles provide the abstract frames of ethical norms and outline the morally ac-

ceptable limits of moral relationships [15, 18].

The principle of **respect for autonomy** is expressed in the right of each individual to make their own choices for themselves, following their own plan of life [6, 16]. In general, competent adults have the right to decide whether or not they want to undergo invasive manipulation. For that purpose, they receive complete information on the need for the procedure and the potential risks and give informed consent. Information should include, in addition to procedure risks, the probability of failure and possible alternatives. One of the prerequisites for informed consent is patient's competence, i.e. the patient is able to understand the implications of informed consent and the ability to freely give their consent [17, 18]. Adolescents have a different degree of autonomy and decision-making ability. Informed consent is given by their legal guardians – parents or other guardians. However, it is considered that the physician should provide sufficient and accessible information on the procedure – its type, complications, price and risks, both to parents and minor patients [17, 18].

**The principle of beneficence** requires that medical professionals act in favor of and for the benefit of the patient or what will further the patient's interest. This principle has been fundamental to the medical profession since its beginning.

**The principle of non-maleficence** requires medical professionals to limit the harm to the patient or what will be against his/her best interest. Patient's unrealistic expectations can raise ethical issues and, in order for a healthcare professional to comply with the principle of non-maleficence, he must explain the expected results and the possibility of failure. The physician should assess both the physical and the psychological state of the patient in order to minimize the possible risk, especially when it is not a person with a disease [10]. The registration of a

form of psychosomatic disorder is essential for the success of the procedure and for patient's satisfaction.

It should be borne in mind that the risks of different aesthetic interventions vary depending on the type of procedure, health status, age of the patient, etc. Some procedures do not require anesthesia, while others are under local or general anesthesia. If the patient's expectations are unrealistic and the risks unjustified, the physician has a duty to assume moral responsibility and to refuse to perform an aesthetic procedure. Physician's duty should be put in front of the financial interest in line with the maxim *Primum non nocere* (First, to do no harm).

Both principles (of beneficence and non-maleficence) rest on the fundamental importance of the interest of and benefit to the patient [19]. In the first the focus is on the positive requirement to affirm the interest of the patient and in the second – on the abstinence from actions that will disrupt the patient's interest. It is sometimes difficult to judge whether an action has benefit or harm to the patient. Because the medical benefit may be accompanied by moral harm and vice versa.

**The principle of justice** in medicine is primarily seen in the context of distributed justice and means honest, impartial and appropriate action on the person [6]. This principle requires medical professionals to provide medical care to all those in need. Healthcare systems, despite the variety of funding sources and payment methods, would rarely cover the cost of cosmetic procedures. So these procedures remain in the private sector at the expense of consumers. Those who can afford to pay undergo cosmetic procedure. Even in countries with low economic growth, the demand for aesthetic medicine is rising [20]. Aesthetic medicine can be referred to as a client – user of health services – rather than a patient. But the provider of these medical services should not be just a profit-driven dealer.

## Factors for Increased Demand for Aesthetic Medicine in Adolescents

We tried to summarize and systematize the main motives of adolescents to search for the services of aesthetic medicine. The demand for cosmetic surgery is usually motivated by psychosocial factors.

- Psychological problems: The search for plastic surgery is most often provoked by psychological factors. In some cases, it may be psychiatric disorders (for example, Body Dysmorphic Disorders – BDD). Typical of these patients is that the aesthetic problems they are looking for cosmetic services are not real. Often after a procedure, they are looking for more new interventions to improve their appearance. Patients with such pathology should be consulted with a psychiatrist. The role of the aesthetic physician is to record the likelihood of such disorder and to redirect the patient, following the principle of harmlessness [21].
- Low self-esteem, provoked by numerous factors – beauty standards promoted in the media and social networks; bullying at school; social exclusion. Each of these reasons is real and in the specific cases the real need for the procedure must be assessed.
- Real serious physical problem (severe acne, congenital malformations, disabilities, etc.)
- Aggressive advertising [22] and media induced perceptions [8].
- Public acceptability and complicity of parents (for example, in 2008, over 10,000 teenagers in Italy have corrected their breasts, most of whom have received the surgery as a gift from their parents).

## Adolescent Patient – Features And Rights

Some characteristics of adolescents that distinguish them from adults undergoing aesthetic procedures are as follows:

- Adolescent patients may be considered as a specific vulnerable group. They do not have complete autonomy and their health decisions are often taken by their parents and legal guardians [18]. Even more delicate are cases in procedures that do not aim at restoring the health of the individual and, as in aesthetic medicine, are applied to healthy individuals [9].
- Adolescents are still developing physically, mentally and emotionally. Unrealistic expectations and underestimation of medical risks are characteristic of them because of their social immaturity.
- In any case, besides the medical assessment, the physician should also assess the emotional maturity of the patient-customer.

## The “Doctor-Patient” Relationship and the Specific Role of the Physician in Aesthetic Medicine

The “doctor-patient” relationship is fundamental to medical ethics. The health and interest of the patient are leading for the physician. The Declaration of Geneva of the World Medical Association states “The health of my patient will be my first consideration” [23]. In the present case, this relationship has two distinctions: 1/ the patient is more like a client, as discussed above; and 2/ the patient is a minor and cannot declare their own interest by themselves due to lack of autonomy.

Aesthetic medicine can be referred to as a client-user of health services rather than a patient. As we mentioned earlier, considering fairly distribution of resources in healthcare, aesthetic services are in the private sector.

Adolescents cannot give informed consent on their own. Although they have no legal capacity, many are able to relate cause and effect and to cover different tests that assess

their competence. In the case of cosmetic procedures, adolescents play an essential role in the decision-making process and the discussion with them is just as important as the one with the parent. Minor patients may have acquired autonomous capacity, which is not always directly dependent on the age of the patient. The relationship between the parent’s authority and the youth’s freedom is dynamic. In the event of a discrepancy between the wishes and expectations of parents and children, the physician must always act in the best interests of the child; to reduce the potential adverse consequences, including physical suffering, pain, stress and death; to respect the spiritual and cultural values of the family and the child.<sup>18</sup> In the case of a significant risk for small aesthetic benefits, procedures should be refused even with the consent of the parents.

Adequate communication with the patient is a mandatory professional characteristic of the physician [6]. Communicative skills are not simply granted, they are subject to improvement. Working with healthy individuals with certain expectations and wishes poses new challenges for medical professionals. The patient-client is not dependent and vulnerable, but demanding.

## Professionalism and Legal Framework

According to the definition of Epstein and Hundert professional competence is the “habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served” [24]. Professionalism in medicine is guaranteed by professional codes, ethical frameworks and rules of good medical practice. This happens in the context of a more comprehensive legal framework [6].

Many European countries are introducing tougher rules to protect adolescents under-

going aesthetic medicine. In Austria and Germany, adolescents under the age of 16 cannot undergo aesthetic surgery. Future patients between 16 and 18 years of age undergo a mandatory psychological assessment and need the consent of their parents [9]. Legislators in Italy have introduced a ban on breast plastic surgery in minors [8].

In the field of aesthetic medicine there are ethical dilemmas which, given the increase in these procedures worldwide, require increased attention. Therefore, the scientific community develops relevant professional codes and ethical frameworks. The International Society of Plastic Surgery, for example, introduces a code that guarantees the preservation of human dignity, academic and practical skills of involved professionals. Adolescents are a specific vulnerable group with varying competence degrees, but without the necessary autonomy for self-informed consent. In each particular case, the physician should consult the adolescent, evaluate their expectations, seek a balance between risks and benefits, and act in the best interests of the patient.

Professionals, beyond knowledge of the legal framework of their country, must know the basic principles and rules of medical profession, the ethical codes and the rules of good medical practice in the specific field. The introduction of such rules in aesthetic medicine is necessary and a guarantor of the quality of medical services. Continuing training in communication skills is a prerequisite for better coping with ethical problems in the practice of aesthetic medicine where patients have client characteristics.

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## Pseudosciences/Pseudotherapies



*Jerónimo Fernández-Torrente*

For Karl Popper, Austrian philosopher and father of critical rationalism, the boundary between science and non-science was in the way that scientific theories make verifiable and therefore falsifiable statements and predictions and are discarded or refuted when those checks do not pass. The character of pseudo-science is not given by the subject itself, but by the statements on the basis of which their study is constructed.

The concept of pseudoscience brings together beliefs or practices that are considered as based on a scientific method without this being true; these beliefs or practices do not follow a valid and recognized scientific method although they are falsely presented as scientific, hence their simplest definition of “false science”.

Pseudotherapy is defined in a broad sense “as a proposal for cure of diseases, relief of symptoms or improvement of health, based on criteria without the support of available evidence”.

It cannot be doubted that current medicine based on the experimental scientific method and forming the basis of our National Health Systems has achieved great milestones and benefits and manages to cure many diseases, unthinkable a few years ago, although it has serious financing problems, is aggressive in many cases and is accompanied by a series of non negligible adverse events and effects. Furthermore, it cannot always meet the expectations of citizens. These are perhaps two problems of current medicine, the adverse effects /events and uncertainty of results in the case of some serious diseases, which create the breeding ground for the offer of pseudotherapies.

The vast credulity and lack of critical thinking has always had a subscription in the most vulnerable population groups, i.e., especially patients with serious pathologies (although anyone can be vulnerable due to lack of academic preparation in a concrete aspect, relying on inadequate sources of information, going through a period of physical or mental weakness, etc.). In the collective imagination there is the figure of the “snake oil salesman” or “hair-growth vendor”. The mechanisms and strategies are exactly the same as those of these classic figures, only adapted to modern times by accelerating their dissemination with the tools provided by the Internet and social networks.

Indeed, in this spurious offer, current technological tools that can be introduced in any field play a fundamental role. Yes, there are groups or organizations interested in the dissemination of pseudotherapies, but any citizen with a computer can break into the privacy of a citizen who is sick and in a situation of extreme vulnerability, dissatisfaction or emotional disorder making them an easy target of any unscrupulous charlatan with pseudoscientific theories.

Therefore, the first step of the General Medical Council of Spain has been the creation of an Observatory that includes an interpretative analysis of 139 non-conventional therapies and techniques, almost all referenced in the Ministry of Health, Social Services and Equality document since 2011. <http://www.cgcom.es/observatorio-omc-contra-las-pseudociencias-intrusismo-y-sectas-sanitarias>

Among the most dangerous pseudotherapies this Observatory analyzes are those related to the area of the so-called new Germanic medicine, a method created by Ryke Geerd Hamer, and the two variants of biodecoding and bioneuroemotion which have attracted many followers and deceive people with false hopes of healing all kinds of diseases, from cancer to malaria, AIDS or autism.

Among adherents are also well-known people who practice impunity with sanitary intrusion and profit, taking advantage of the weakness of patients and selling products that are prohibited by the Medicines Agencies in Spain and Europe, such as Sodium Chloride - MMS, industrial-use bleach diluted to 28%, with the false message that it can be used to cure cancer and other serious processes.

We can remember the case of Hamer, who in 1994 deceived around 3,000 cancer patients in Spain who stopped chemotherapy and many of them died. He was sued and fled to Germany, Italy and later France, countries in which he was jailed; later he returned to Spain where he was also convicted and jailed. In 2007 he settled down with several of his clinics in Norway.

“The funny thing is that, after two decades, these events are repeated and we have well-known personalities, some of them doctors, who are sued, who proselytize this pseudotherapy/pseudoscience,” the so-called new Germanic medicine, that “is neither medicine, nor is it new; it is deception that also

has a sectarian element to it because the patient abandons their treatment and departs from their relational environment because they tell them that this makes healing more difficult”.

One of the main problems is the legal vacuum and the lack of information, something that many unscrupulous people take advantage of. Although there are health professionals and non-professionals who use these techniques/therapies as experimentation with good intention, there are many others who really “deceive people saying they will cure important diseases when there is no evidence of this cure”.

All our Medical Deontology Codes and legislation on public health advertisements in many of their issues prohibit deception of citizens and patients; they also prohibit medicines and procedures

that have no proven evidence and their use through deception, and public administrations are responsible for it, sharing responsibility with our professional corporations.

We must highlight the issue of minors and the responsibility of parents /guardians who act, very often, on the basis of misinformation, and also the responsibility of the authorities and professionals who do this and who are completely outside the Law.

These pseudotherapies “must be subjected to scientific rigor and evidence, something that is not currently happening”. “The strategy that the person against pseudotherapies must prove why they are against them, is fallacious and deceptive; it is used when there are no credible arguments, neither scientific, nor experimental, nor security of any practice or technique.”

We must defend conventional scientific medicine and experimental scientific medicine, which are based on public health systems in the European environment, Spain including, of course, and which is our obligation and responsibility to defend because it is an essential part of our professional and ethical commitment with the medical profession and with society as a whole.

On the part of professional, academic, administrative and also scientific organizations “we must know how to respond with force to the challenge of this parascientific and paramedical universe that is very harmful to the health of citizens, for the security and the rights of our citizens and patients and for our welfare state.”

*Dr. Jerónimo Fernández-Torrente, Treasurer  
General Medical Council of Spain*

## New IFPMA Code of Practice 2019



*Thomas Cueni*

IFPMA (International Federation of Pharmaceutical Manufacturers & Associations) represents the research-based pharmaceuti-

cal companies and associations across the globe. The research-based pharmaceutical industry's 2 million employees discover, develop, and deliver medicines and vaccines that improve the life of patients worldwide. Based in Geneva, IFPMA has official relations with the United Nations and contributes industry expertise to help the global health community find solutions that improve global health.

Thomas B. Cueni is Director General of IFPMA since 1 February 2017. Prior to joining IFPMA he was Secretary General of Interpharma, the association of pharmaceutical research companies in Switzerland. For many years Thomas Cueni has been involved in the work of the European Federation of Pharmaceutical Industries and Associations, EFPIA, where he most recently served as Vice-Chair of the European Markets Committee and association represen-

tative on the Board. He represented the industry on the EU High Level Pharmaceutical Forum, was Chairman of EFPIA's Economic and Social Policy Committee and Chairman of the EFPIA Task Force on the EU Commission's Pharmaceutical Sector Inquiry. Thomas Cueni also represented Interpharma, which he successfully transformed from the association of Swiss Rx companies to the association of pharmaceutical research companies in Switzerland, on the Council of IFPMA.

Prior to his appointment with Interpharma, Thomas Cueni had a career as a journalist, inter alia as London correspondent for the “Basler Zeitung” and “Der Bund”, and he served as a Swiss career diplomat with postings in Paris (OECD) and Vienna (IAEA, UNIDO). He studied at the University of Basle, the London School of Economics, and the Geneva Graduate Institute for International Studies, and has Master degrees in economics (University of Basel) and politics (London School of Economics, LSE).

An efficient healthcare system depends on mutual trust between all parties – but how should that translate concretely into the day to day reality of whether a healthcare professional should be given a subscription to a journal or a box of chocolates by a pharmaceutical company? So while the most important part of the R&D-based pharmaceutical industry's work is the discovery of new medicines and vaccines, it also needs to develop, promote, sell and distribute them in an ethical manner and in accordance with all the rules and regulations for medicines and healthcare. It's not just what we achieve that matters, but also how we achieve it.

In today's fast-changing world, what might have been considered normal business practice a few years ago may no longer be acceptable. For our industry, what is essential is to constantly try to live up to the trust that so many – patients, healthcare professionals, regulators, policy makers from all over the world – have in the medicines and vaccines we make.

Our R&D-based pharmaceutical industry Code of Practice was first drawn up in 1981, and it was the first one of its kind for any business sector. Indeed, it set a precedent for many other global self-regulation initiatives of industry practices that were to follow. Initially, correct information on the effects and side effects of medicines were at the core of the Code and was necessary to build trust among patients, healthcare professionals, and other stakeholders for the innovations we would bring to the market. Today, through periodic updates of the Code, expectations regarding compliance are much more comprehensive.

The last IFPMA Code revision in 2012 (current version, in force until 31<sup>st</sup> December 2018) saw its scope expanded beyond just focusing on our promotional practices to cover all our company members' interactions with healthcare professionals, medical institutions and patient organizations. Over the past two years, we have been revising

this Code by consulting with our members from all over the world. Our members are now getting ready to implement a new version of the global Code, which will be effective from 1<sup>st</sup> January 2019<sup>1</sup>.

With this sixth edition of our [IFPMA Code of Practice](#), we are again setting the bar higher than with previous Codes. The 2019 Code is marked by two important changes. First, several sections have been updated, including the introduction of a ban on gifts and promotional aids (for prescription medicines). Second, we have developed our "[Ethos](#)", the ethical foundation of IFPMA. This addition aims to shift the approach to changing behaviors from a rules-based to a values-based Code. The intention is to ensure our members embrace the values and principles that underpin the requirements of the Code.

The new global Code has been aligned with current European and US guidance and resulted in a global ban on gifts and promotional aids for prescription-only medicines. Any exceptions based on the custom of gifts to mark significant national, cultural or religious events (for example, mooncakes or condolence payments) have been removed. IFPMA members are also banning all promotional items for healthcare professionals for use in their offices (including post-its, calendars, diaries, etc.). The only items that can be provided to healthcare professionals – in the context of company organized events – are company-branded pens or notepads in order to take notes during the meeting.

We have also added the new category of Informational or Educational items. These are things like scientific books, journal subscriptions or memory sticks with educational data that may be provided to healthcare professionals for their own education or for the education of patients, provided

that the items do not have independent value. Product branding is not allowed, in the same way as for items of medical utility (such as inhalers, or devices to learn how to self-inject).

As R&D-based pharmaceutical companies are the innovators behind most new medicines and vaccines, they are best equipped to share much of the information on medicines and their application, and have the responsibility to share this scientific knowledge with healthcare practitioners. Today's fast pace of medical innovation requires a continuous dialogue to ensure that patients have access to the treatments they need, and that healthcare professionals have up-to-date, comprehensive information about the medicines they prescribe. We think that the so called "goodies" or "promotional aids", even if they are of minimal value, send the wrong message, as they trivialize the important, professional relationship that must exist between our representatives and the healthcare professionals. This relationship is based on a mutual exchange where both sides win by sharing expertise and scientific knowledge, enabling the development and effective use of new medicines.

The latest IFPMA Code emphasizes the educational nature of these important interactions and supports high-quality, patient-centered health services and further focuses on the value we bring to patients, and to society as a whole.

Trust remains the crucial bedrock of these exchanges and IFPMA encourages doctors, pharmacists, nurses and patients to become aware of our updated ethical standards. The better our stakeholders understand our standards and hold us to account, the easier it will be for us to live-up to our commitments.

By Thomas Cueni, IFPMA Director  
General and co-chair of the APEC  
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<sup>1</sup> <https://www.ifpma.org/subtopics/new-ifpma-code-of-practice-2019>

## Interview with Dr. Otmar Kloiber, WMA Secretary General, on the Upcoming WHO Global Conference on Primary Health Care in Astana, Kazakhstan, 22–23 October 2018

In September 1978, the WHO staged the first International Conference on Primary Health Care in Alma-Ata, Kazakhstan (at that time a part of the Soviet Union). The outcome was a document widely known as the Alma-Ata Declaration on Primary Health Care. The conference also started a program called “Health for All in the Year 2000” setting targets that should improve the health status of all nations.

Forty years later, the WHO has called for a second Global Conference on Primary Health Care, hosted this time by the government of Kazakhstan, along with WHO and UNICEF, in its new capital Astana. Peteris Apinis, editor of the World Medical Journal talked to Otmar Kloiber, Secretary General of the World Medical Association about the significance of this conference.

**Apinis:** Next month health ministers, representatives of WHO, UNICEF, the World Bank and the International Monetary Fund will meet in Kazakhstan for the 2<sup>nd</sup> Conference on Primary Care. Will it be as successful as the first conference?

**Kloiber:** I hope it will be a much bigger success than the Alma-Ata conference.

**Apinis:** You sound as if you were not satisfied with the outcome of the Alma-Ata conference. Why is that?

**Kloiber:** Alma-Ata was the biggest WHO event ever, however the results were patchy or mixed, to put it kindly. The Alma-Ata Declaration reads well, but what many countries took away from it was no more than a minimalist approach. Primary

Health Care became a cheap substitute for real care. This has led to disappointments and misunderstandings, and sometimes to a rejection of the concept of Primary Care. This must not happen again. Primary Health Care should be at the core of every health care system, even of the most advanced and comprehensive health care systems. Primary Health Care should not be a dead-end road and should not be seen as a second-class concept for poor people.

**Apinis:** Do you mean that Primary Health Care is only for affluent countries?

**Kloiber:** No, no it is truly for everyone. Health care systems should be organised around a solid core of Primary Health Care providing prevention, medical treatment, dental care, rehabilitation and palliative care. This should offer pathways to secondary and tertiary care. But when starting up a health care system, your focus will have to be on Primary Health Care as this provides care options for most health needs. But again: it must not be a dead-end road. When serious conditions and trauma cannot be dealt with, frustrations will rise. Comprehensive health care systems have to be built around the core of Primary Care.

**Apinis:** Why now after 40 years?



**Kloiber:** Yes, this is late. In fact the WHO issued a remarkable report in 2008 entitled “Primary Care – Now more than ever”, but obviously this advice was not taken. Now the WHO is looking into Universal Health Coverage. This is the most ambitious WHO program ever: the desire to bring affordable health care to everybody, not sectorial, siloed programs, not episodic care – real health care for all people. If you want to achieve this, Primary Health Care is the first step on the delivery side.

**Apinis:** What is on the other side?

**Kloiber:** Aiming for Universal Health Coverage means, in the first instance, tackling the Social Determinants of Health. Without bringing justice – some people call it “social justice” – to people Universal Health Coverage will remain wishful thinking. And yes, this must include providing the necessary financial resources. If countries don’t understand that health care is an investment and not an expense they will not get this done.

**Apinis:** What mistakes should be avoided this time?

**Kloiber:** It needs a comprehensive approach, starting with the Social Determinants of Health, and it must not end with a high-quality Primary Care service – although establishing this first is a sound idea. After Alma-Ata, countries reduced their ambitions to a minimum of care – they thought the cheaper the better. In some places where health targets were aimed at everything else got forgotten. The typical “window-dressing” problem: Fulfil the targets to look good, drop the rest. This can easily turn into a fatal concept.

**Apinis:** What is the role of medical doctors in Primary Health Care?

**Kloiber:** Everybody who needs a doctor should be seen by a doctor. Medical doctors have the highest level of competency and they should lead the primary care team. This doesn't mean that doctors have to direct and command everything. There are other professionals that can contribute with their expertise, but in the end this is about health and medicine. Medical doctors should be in charge wherever this is possible.

**Apinis:** This sounds very logical, why are you stressing it?

**Kloiber:** Firstly, doctors are a scarce resource in many countries. We must understand that in the short run a doctor will not be available everywhere. Secondly, there are groups and donors who again want to “save money”. At the World Health Assembly this year we heard all too often that doctors are too expensive. Some want to focus only on Community Health Workers; others such as the OECD prefer nurses as leaders of Primary Care teams, giving physicians more of a bystander's role. In my opinion these are perfect recipes for repeating the mistakes of 1978. Investment in human resources for health must include investment in the education and employment of physicians.

**Apinis:** Is there no role for nurses and Community Health Care Workers?

**Kloiber:** There definitely is. Nurses are desperately needed, for nursing care. Community Health Care workers can support health professionals through outreach work, especially in rural communities. And this again is no simple task. A

lot can be done right now by well-trained Community Health Care workers, and more will be possible in the future with better and more intelligent e-health tools. But this will not replace a nurse, it will not replace a dentist, it will not replace a physiotherapist, a pharmacist or a physician.

**Apinis:** What do you expect from the Astana Conference – or more specifically from the participants?

**Kloiber:** From the WHO: keep aspirations high and do not settle for second best. From politicians: go for Universal Health Coverage, even if it will be a long journey. The Social Determinants of Health have to be on the agenda of every minister in every government and quality Primary Health Care is a sound delivery concept to start with. From donors: support sustainable solutions and not quick fixes that don't last. From doctors: engage for the Social Determinants of Health, for equitable access to health, health care and medical care.

**Apinis:** Dr Kloiber thank you for your insights.

## World Federation for Medical Education. World Conference

Seoul, Korea, April 2019

In April 2019, WFME will hold a World Conference under the common theme of “Quality Assurance in Medical Education in the 21<sup>st</sup> Century”.

In medical education, as in other fields, to attempt to achieve higher quality on a global scale is a difficult endeavour. The needs of societies vary considerably from region to region, even from country to country, while migration of health care professionals creates the need to achieve a degree of global comparability: to find a balance is challenging.

The World Conference is a chance to bring knowledge and experience together and find common ways to enhance the quality of medical education both on the global and on the local scale.

In the past, the WFME Conference brought significant steps towards improvement.

- In 1988, 30 years ago, the WFME World Conference resulted in the Edinburgh Declaration which set out to alter the character of medical education so that it truly meets the defined needs of the society in which it is situated.
- In 2003, the WFME Conference was devoted to the WFME Trilogy of Global Standards for Quality Improvement, which gained international endorsement. Since then, the Standards have been widely used and adapted for the needs of particular regions and societies.

For 2019, the focus remains on the quality of medical education world-wide: its current state, its challenges and progress, and the view of the future. The Conference will attempt to answer several crucial questions:

### Are your practices in accreditation the right ones?

It is widely understood that accreditation of medical education ensures the quality of education. However, the mere existence of an accreditation system in a country or a region does not guarantee that the system will result in trustworthy decisions; this requires the accreditation system itself to operate in a robust, transparent and norm-referenced way. WFME attempts to promote quality accreditation through its [Recognition of Accreditation Programme](#).

### What is happening in the WFME Recognition of Accreditation programme, and how should an accrediting agency prepare for it?

The Recognition of Accreditation sessions will present the system of assessing the quality accrediting agencies, as WFME has developed

and implemented it, and the lessons we have learned from the agencies we have already visited, experiencing various contexts, systems and solutions, the differences – but also many unifying aspects.

### How should you develop standards for education that are right for the context of your medical school, your country or your region?

The Global Standards for Quality Improvement will once again be a prominent topic; in the dedicated sessions, participants will hear about the experience of developing standards for medical education in particular context and learn how they should be used. There is a common misconception that the WFME Standards are to be used as a prescriptive tool. WFME regularly tries to dispel this notion, as the Standards always need to be adjusted to the needs of the particular context and society.

### How can we help to make the transition from medical school, to postgraduate education, and on to a fully-established medical career while maintaining a lifetime of learning and quality improvement?

Medicine is a dynamic art and science, and lifelong education of professionals is a vital requirement. There needs to be a discussion on how to train future doctors to approach and tackle this component of their work, and how medical education should be structured to account for the variability of the profession.

### What are the questions to be answered in developing accreditation of postgraduate medical education?

While the accreditation of basic medical education is demonstrably in progress – although, of course, there is still a long way to go to achieve an ideal state – the accreditation of postgraduate medical education is a very complex process that works well in some jurisdictions, but is yet to be addressed in a constructive way on the global level. The sessions dedicated to this theme will attempt to map out the field of postgraduate medical education and lay out a plan how quality of such a diverse field can be assured in a systematic way.

We invite all interested parties – representatives of physicians, educators, researchers and students from all over the world – to come and join us in discussion about the challenges we are facing world-wide and opportunities we have to improve the quality of medical education.

Date of the Conference: 7–10 April 2019

Abstract Submission Due: 31 October 2018

Notification of Acceptance: 14 December 2018

Early Registration Due: 31 January 2019

On-line Registration Due: 29 March 2019

Please follow the conference website [www.wfme2019.org](http://www.wfme2019.org) for the upcoming details about the programme and more.

