Patient Empowerment

A discursive shift in the EU's institutional response

By

Ágnes Rabóczki

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Supervisor: Professor Judit Marcella Sándor

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Abstract

The thesis examines the discursive shift that took place in official European Union health care rhetoric concerning the issue of patient empowerment under a period of 24 years. The paper argues that patients have started to withdraw from institutional medicine due to their continued discontent with the quality of doctor-patient interactions. Because of their disempowered state, patients have begun to form their own communities, self-monitor their health and increasingly voice their dissatisfaction with institutional medicine. On the theoretical grounds of discursive institutionalism, the thesis suggests that due to such social mobilizations as patients' rights and empowerment movements, civilians are able to affect change from the bottom-up and tailor future policy-making to their needs. Through the qualitative methods of frame and thematic analysis, the paper was able to pinpoint patterns in the EU's official discourse. Thus, the thesis studied official EU Commission health care strategies in order to assess the prominence of patient empowerment under every EU administrator cycle. It further observed whether the external social pressures were palpable enough to be apparent in official health care strategies. The findings suggest that there has been an ever-increasing shift from the masses to the individual; from the many to the few; and from the general to the personalized. The EU is faced with the burdening 'containment pressure' of increased consumer demand for patient-centered care, whilst witnessing the gradual decrease of health care funding. The thesis concludes that patient empowerment may be a solution for these pressures and remedy patients' frustrations as well as benefit the EU on both economic and political levels.

Dedication

This work is dedicated to the people that provided me with support and care throughout this year. I am so happy to have met you and to have shared this experience with you. I love you Kirill, Lucy, Marcella, and Greg.

Furthermore, it is dedicated to the struggle of a brave little boy called Bende Gábor.

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1. Introduction

> "The patient experience of care is something to ignore at your own peril….It's a huge differentiator."
> -Chuck Lauer,
> Health care author

Medicine, technology and pharmaceuticals have developed at an exponential rate over the past century. The attitudes of medical professionals and their patients should have progressed in line with technology, but some argue that they have become evolutionarily complacent. Observing the rapid changes in medical technology is a visible process for the general populace; it is a tangible field with clear benefits, developments, and products. Few, however, discuss and track how these substantial transformations have impacted and altered the interactions between patients and doctors. Currently, a new trend of e-patient communities and online advocacy groups are taking over the formerly institutional role of patient support. This development in addition to the emergence of online resources that provide medical self-monitoring services, for people in need of some form of medical attention, is rapidly altering the patient-consumer landscape. These online communities are comprised of websites such as: Patients Like Me, Ben's Friends, and 23 and Me, are boasting immense success within the public health care discourse. Their aim is to provide a support system for patients enabling discussion grounds for their treatments and symptoms by aggregating individuals suffering from similar ailments. They also pressure health institutions to induce health policy changes and increase patient empowerment. These groups achieve their ends through petitions, strikes, boycotting certain drugs, raising general awareness, and by submitting amicus curiae briefs for legal input during pharmaceutical and medical court cases. Through such sites, patients are able to learn about alternative treatments, treatments abroad, and experimental procedures. Another accompanying consequence of the popularization of patient communities is the increasingly widespread ‘Quantified Self Movement’. This phenomenon is rooted in Silicon Valley, with its inception in the early 2000s; the intention was to help individuals self-track their biometrics and turn them into actionable data. Consequently, this data was intended to provide milestones on the basis of which users could improve on their personal health. Examples off this movement and the associated technologies are: iPhone, Pebble watch, Fitbit, Nike+ or various apps that include pedometers or GPS for mobile devices. The aforementioned apps and gadgets allow patients to gather data about themselves and potentially use this during medical visits, becoming more educated and aware of personal biometrics.

The aforementioned efforts share the common denominator of attempting to turn away from the traditional one-direction health care consultations, by allowing patients to, “Take healthcare back into their own hands”. This aims to create a new generation of patients who have a more dynamic relationship with their own body-, general practitioners and healthcare consultants

This shift has led to a recently observed trend of individuals mistrusting public health care, physicians and pharmaceuticals. This shift in attitude is due to patients gradually becoming tired of the usual ‘script’ that takes place during doctor-patient interaction (Godolphin 188). They are tired of feeling as though they cannot share certain information with their physicians, often due to shame or guilt. Further, patients have also become fatigued with the tendency of physicians to not share treatment information, alternatives or general results with them. Therefore, these online communities took on a more nurturing and supportive role that many patients found modern medical care lacks. Research shows that patients are able to heal better when they are surrounded by a supportive community (Segal 39). Furthermore, by engaging in these supportive online communities patients are given an opportunity to accept responsibility before their peers to take on a more active role in managing their health care conditions. I am confident that the patient has started to ‘slip out’ of traditional health care institutions due to not being empowered enough to participate in managing their own condition. Moreover, I am certain that this trend has sparked a change in official EU discourse. This becomes clear through the study of the EU Commission’s official Health Care Strategies, as presented later in the paper.

There has also been an institutional reaction to patient empowerment not only within the medical institutional discourse, but also in governmental policymaking. One of the EU’s first steps in remediation of the issues concerning patient empowerment was the establishment of one of the first active empowerment organizations: the European Patients Forum (EPF) in 2003. The EPF’s mission is to help empower patients through policy initiatives and monitor all EU health care related legislation, as well as work towards benefiting the EU community as a whole; aiding both patients and organizations. Although, it is important to note that the EPF does not hold any legal control. These efforts resulted in a 2009 European Council recommendation on patient safety, which stated “Patients should be informed and empowered by involving them in the patient safety process. They should be informed of patient safety standards, best practices and/or safety measures in place and on how they can find accessible and comprehensible information on complaints and redress systems” (EU Council 151/2 §9). Consequently, the European Union Patient Safety Group was established in 2010. Due to the founding of such organizations, the EU entered the institutional discourse on patient empowerment and has begun an era of improvement in order to further successful health care reform. In order to counteract patients’ shift towards online support communities, the EU Commission began implementing an EU eHealth system. This system aims to be a huge, EU-wide health care database where patients may access their data and search for options within state health care system. Until now, only a handful of member states, with varying degrees of success, have managed to implement eHealth into their systems.

The discussion on patient empowerment began with the evolution of the human and patients' rights movements, which eventually encompassed other sub-fields of empowerment. To date, empowerment means, "the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations" (Segal 37). In the context of health care, the most important issue that patient empowerment revolves around is the battle against information asymmetry between doctor and patient. This empowerment takes shape by allowing people to gain access to one's personal bio-data, medical files, treatment alternatives, opportunity for a second opinion, and more. Due to higher access to medical information people are enabled to become informed patients, i.e. patients who are in full competence of their conditions, possible treatments and are able to provide informed consent to their choice of medical therapy, thus being an overall informed patient. There are many skeptics of the patient empowerment model, and are in more favor of a paternalistic viewpoint. This may be the result of the conflict of the underlying models; thus, shared decision-making model versus the technocratic decision-making. Contemporarily, the technocratic approach is the one that is easier to connect to for traditionalists and pragmatists. However, research shows that patient empowerment is proven to be beneficial for patients' health conditions. On account of the fact, that, they are taking active part in their healing process; patients are able to take responsibility of their conditions and therefore have higher rates of self-efficacy. Furthermore, patient empowerment also has strong economic benefits, such as providing a driven market by enabling citizens to become informed patients they are able to directly communicate their demands to policy-makers. Patient empowerment is vital to successful EU health care reform and will need to be implemented to face the omnipresent threats of socioeconomic and demographic change. Socio-economic factors playing into this demographic warp across Europe are: aging populations, increased longevity of citizens, rising numbers of patients with chronic diseases, and more. Empowerment will become the most effective *(in terms of costliness versus efficacy)* method for the EU to allow the health care market to meet the demands of its consumers. Thus, the EU must prepare to respond to these demands and reform health care in a sustainable way.

The EU faces immense obstacles in implementing health care initiatives. The problems surrounding acquiring funding, as well as the difficulty of juggling EU member states individual national health care systems, are at the pinnacle of the organizational problems faced by the EU. Such complications present a great obstacle in initiating transnational health care legislation, such as the Oviedo Convention (1997). Further, there are huge gaps in the overarching quality, availability and overall state of health care amongst member states. However, despite the disparity, many Member States share similar healthcare and demographic concerns. Many of these aforementioned issues create direct economic pressure on both state and citizen. This is pressure is the result of increased health care costs and increased demand, and the demographic aging process.

I believe patient empowerment may present an all-encompassing solution to the aforementioned problems on economic, social and political levels. Firstly, research shows that through empowerment patients are enabled to become ‘informed patients’. Thus, they are able to engage in meaningful doctor-patient interactions and better communicate their concerns. Secondly, by becoming empowered, informed patients are able to take on an active role in the management of their condition. This self-monitoring carries many benefits, for example; research has shown that signs of improvement were measured more swiftly in empowered patients than with their disempowered counterparts. Additionally, through empowering patients the health care system will be able to receive direct feedback about consumer satisfaction and will be able to adjust the market accordingly. Consequently, patient empowerment will provide for a driven market that is directed by the consumer, rather than out-of-touch institutions. Ultimately, through this decentralization of health care, it would provide for better means of patient interest representation. With the propagation of regional health care services, the gap between institutions and patients would decrease. Consequently, regional policy-makers receiving direct feedback on their health care initiatives would be able to more effectively react to patient responses.

The paper aims to reflect, how official EU Commission discourse has changed as regards to patient empowerment within EU health care policy. In order to identify this discursive shift, through the tool of thematic analysis, I study a series of official EU Commission documents through the qualitative method of frame analysis. The utilized data body consists of official EU Commission Health Strategies dating back to 1996, for a total of four texts used for analysis. The research is separated into two compatible time periods, the dividing line being the year 2003. The year was chosen because of the establishment of the EPF, thus it is the year the EU chose to enter the institutional discourse on public health and patient empowerment. The findings of the research show that patient empowerment has received increasing attention within EU Commission discourse over the past years. The frames in which patient empowerment are presented differ greatly, and are therefore an important mirror for the observer to judge the EU's official stance towards the betterment of patient-centered care. Consequently, one may be able to identify the current pitfalls in the health care system and recommend solutions for future health care policy-making.

2. Theory and Literature Review

Due to the increased traction of coverage concerning empowerment, the topic has seen an escalation in scholarship. However, in order to understand the inception of this movement and its surrounding legal environment, the thesis relied on the human rights scholarship of such authors as Gruskin, Mills and Tarantola (Gruskin et al. 2013). According to the authors, the discussion on human rights truly began after the 1945 United Nations Universal Declaration of Human Rights, which was identified as common principle amongst all states. Subsequent to the Nuremberg Trials and the end of the Cold War, health and human rights developed simultaneously, but separately. It was the 1980s AIDS epidemic that melted the two concepts together. Few years later, reproduction rights and legal issues concerning In Vitro Fertilization (IVF) treatment would have the same effect. The legal context around the aforementioned issues became intrinsically complex. Policy-making had to be encompassed into the legal dominion of decision-making, due to the fact that it connected governmental, non-governmental and civilian stakeholders. In the wake of emancipation movements of the 1960s, significant influencers of health empowerment literature were born (Hoffman 2003). Protests involving such issues as women's rights, voting rights and overall civil rights all contributed to civilian demand for empowerment. Framework documents, such as, the Amsterdam Treaty, drafted by WHO and the Dutch government (1994) and the Oviedo Convention, drafted by the Council of Europe, (1997) have provided the European Union response to advancing health care rights and bioethics in biomedical human rights issues such as informed consent, the right to health, the right to access health data, right to privacy, doctor confidentiality, etc. The latest definition of health was provided by the World Health Organization. It states that "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Official Records of the World Health Organization, no. 2, p. 100). This definition already aims to mirror the change of discourse concerning the modern role of health care; it has overarched the boundaries of physical illness and expanded towards psychological and social well-being.

One of the current issues is the crossroads, where health care policy-making and human rights cross, that Mann et al. discuss in their article titled *Health and Human Rights* (2013). The issue they draw upon is the current pressures of the shift from social health care to individual medicine, the health of populations versus the health of the individual. Governments must grapple with an increased demand for individual, patient-centered care meanwhile their health care budgets are gradually decreasing. Thus, policy-makers must choose between providing affordable dissatisfying to mediocre health care services to masses or costly individual medical attention to a chosen few.

The gap between institutional medicine and patients has become apparent. Moreover, patients are tired of the information asymmetry between them and their doctors. With the evolvement of the Internet, patients can now conduct more research about their conditions than ever before, sometimes to their undoing. Bertalan Meskó is an esteemed Hungarian medical doctor, professor, and futurist. In an interview with mHealth (Oct. 06, 2014), he pointed out that patients are fatigued by attending medical consultations where doctors are more preoccupied with the immense amount of bureaucracy they have to do after every patient. Instead of examining their patients physically, mentally, providing support, understanding their condition, they are restrained by the overly complicated bureaucracy that has taken over modern health care.

The research's primary source for the definition and conceptual framework of patient empowerment was provided by Leonie Segal in her article titled: *The importance of patient* *empowerment in health system reform* (1998). She defines empowerment in the following way "Empowerment in its most general sense, refers to the ability of people to gain understanding and control over personal, social, economic and political forces in order to take action to improve their life situations" (Segal 37).

Consequently to the dehumanized nature of modern institutional medicine, patients have started to turn towards other modes of healing. In their search for empowerment, patients have begun to consult another and monitor their personal health. Some websites that offer said services are Patients Like Me (www.patientslikeme.com), Ben's Friends (www.bensfriends.com), and 23 and Me (www.23andme.com). Eric Topol, M.D., points out in his book, The Creative Destruction of Medicine (2012), that personalization has become a key element in the modern mindset. According, to the aforementioned trends in human rights, there has been an observable shift from the masses to the individual; from the many to the few; and from the general to the personalized. We aim to personalize not only our cellphones, but also our medicine and medical care. The patient should be present as an individual, not as a member of a group or a statistic. The Quantified Self Movement has been the forerunners of digital health monitoring devices, which essentially provide means of direct feedback, and satisfies the patients' demand for evidence based medicine.

Both Nicholas Brody and O'Connor et al. point out in their articles that evidence-based medicine is one of the key concepts of patient empowerment. Patients now want to undergo treatment that they understand to be a perfect fit for their condition. Patients no longer want to be treated on a trial and error basis. This, O'Connor et al. dubs as "preference-sensitive treatment, where decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice" (O'Connor et al. 716). In order to become an informed patient one has to actively engage in medical treatment through extensive research. Examples of this active research/involvement are: risks and benefits of certain treatment options, inquiring a second medical opinion, search for patients with similar cases, and considering personal biometrics. However, this is not a one-sided process; doctors have to engage in “patient-centered communication” (Martinez et al. 3849) by enquiring personal treatment preference.

Alongside, concepts such as evidence-based medicine and informed patient, one must also mention Informed Consent (IC). It is “when a health care provider discloses appropriate information to a competent patient. The patient can then make a conscious decision to accept or refuse treatment” (Cohen 5). To date, all health care interventions require an IC, this may be a general form or one requiring a signature (e.g. for interventions such as surgery or anesthesia). The medical care practitioner must ensure that the patient is competent and understands the risks of the procedure. The aforementioned concepts are all a part of a newly formed model of doctor-patient interaction; the shared decision making (SDM) model. The SDM model, also called the ‘Deliberative Model’, is, “a process by which doctor and patient consider all available information about the medical problem in question. This information includes the treatment options and consequences, and then considers how these fit with the patient’s preferences for health states and outcomes” (Frosch, Kaplan 285). It requires active participation from both parties as well as a great deal of honesty concerning goals and preferences of a certain treatment. The Shared Decision Making model is becoming increasingly popular within contemporary medical practices. It advocates for a “meeting of experts” (Godolphin 186) approach between doctor and patient. Consequently, the doctor is present as an expert of her field, holding the necessary medical knowledge; the patient in this approach is present as an expert of her body and her state of health. Thus, responsibility is shared between the patient and the physician regarding treatments and consequences. Many advocate for SDM because of its flexibility towards patient variance. On account of the high degree of uncertainty, patients will react to certain medical treatments; SDM provides a platform for discussion about preferences as well as provide an opportunity for patient autonomy. Everybody has the ethical and legal right to direct what happens to his/her body as well as the right to rely on their doctor to provide them with all health care related details. Research carried out by Martinez et al. examined whether patient-clinician engagement (PCIE) affect the feeling of being informed, thus providing for higher rates of treatment decision satisfaction (TDS). The research observed the responses of patients from the Pennsylvania Cancer Registry and worked with a randomly drawn sample of N=2013. They found that patients with higher PCIE were consistent with higher rates of TDS as well as feeling informed. Thus, patients who feel informed and have established communication with their clinicians also experience a feeling of satisfaction concerning their chosen treatment option.

With the rising demand of patient-centered care and rising health care concerns, institutions must look forward to radical health system reforms. However, due to extensive gaps between institutional medicine and patients, reform will be near to impossible without the utilization of patient empowerment. The EU has taken steps in order to bridge this problem in health care, by helping in the establishment of patient empowerment advocacy groups such as the European Patients Forum in 2003. The paper will analyze in later chapters, how patient empowerment has also debuted in many of the European Union Health Care Strategies, although with varying emphasis.

Literature on the institutional stance towards patient empowerment is rather limited when examining the European Union online archives. In recent years, academia has mainly concentrated on empowerment research within certain disease groups, especially concerning chronic and rare disease patients. Most publications on the issue derive from smaller patient advocacy organizations, which may be affiliated with the EU. However, this does not mean that they are necessarily linked to its organizational structure. Although, there are important EU patient empowerment groupings such as the EPF or ENOPE (European Network on Patient Empowerment), they act as umbrella organizations that oversee several smaller social groups. Hence, institutional publications are mostly in the form of brochures and information flyers, than academic articles. The most relevant resources for the thesis were the Health Care Strategies published by the EU Commission approximately every 6 years. These Strategies are further supplemented with mid- and ex-post results that evaluate the relevant cycle. The Strategies act as guidelines for Member States and are intended to trigger future policy-making. However, the EU faces a great many challenges in implementing universal legislation, especially within the field of health care. All 28 Member States have unique health care systems, thus implementing legislation that is applicable to all is unfeasible. As David Wilsford discusses in his article, *Path Dependency, or Why History Makes It Difficult but Not Impossible to Reform Health Care Systems in a Big Way* (1994), path dependency has always been a barrier to implement stark change. These barriers may be existing social and political constructs that manifest themselves in the form of agencies and institutions. He argues that because of the policy-making power these institutions hold, we are bound to repeat past policy paths. I believe this has now become an idea to be contradicted. Information technology has never been more attainable than in our day and age, hence people have more knowledge at their disposal than ever. Moreover, people now have digital platforms to share this newly acquired knowledge on through the use of social media. Citizens have begun to voice their concerns, form groups, produce open letters, support each other, mobilize and more. Consequently, the playing field between citizens and policy-makers is beginning to level out.

According to Vivien A. Schmidt, these trends call for a new sort of institutionalism. Thus, the theory of discursive institutionalism (DI) provided the theoretical backbone for the thesis. One of its most widely acclaimed representatives is the prior mentioned, Vivien A. Schmidt, through her article *Discursive Institutionalism: The Explanatory Power of Ideas and Discourse* (2008). Schmidt names discursive institutionalism as the fourth "new institutionalism" next to rational choice institutionalism, historical institutionalism, and sociological institutionalism. Unlike the old new institutionalisms DI is not "sticky". It has the capacity to simultaneously structure and construct by unfixing preferences and norms. The DI states that political, social, or policy discourses have the power to perform communicative functions. Through these functions actors may publicly express themselves which may affect social change. Schmidt places great emphasis on the significance of discourse, even more so on its "context". She explains that there are two basic forms of discourse in existence; coordinative discourse (discourse amongst policy actors) and communicative discourse (discourse between policy actors and the public). However, there is an interstice between the two types of discourse. Politics and policy-makers generate ideas of what should be done, but do not consult the public sphere, or explain why those ideas matter. Once again, the widening gap between institutions and the public surfaces, as it does between health care policy-makers and patients. Thus, the purpose of discursive institutionalism is to "contribute to our understanding of political action in ways that the older three institutionalisms cannot" (Schmidt 305). Furthermore, it also aims at exerting political influence through the instrument of discourse.

The influence of discourse may lead to further question the agency behind the 'discussion leaders'. "How ideas are conveyed, adopted and adapted, let alone the actors who convey to whom" (Schmidt 309). As such prominent political science figures have observed in the past, as

Bourdieu (1994), Foucault (2000) and Gramsci (1971), the creators of social philosophies are the ones who hold the most power, i.e. the group that retains agency. According to Schmidt, there are two spheres of agency; the policy sphere and the political sphere. Within the policy sphere there is a core group of decision-makers, who create, discuss and implement policies. Agents of the policy sphere may be civil servants, elected officials, experts, scholars, etc. However, Haas points out (1992) that these "epistemic communities" may also be the domain of individuals, such as advocacy networks, activists, entrepreneurs, or mediators. Ultimately, they will serve as a catalyst for change. On the other hand, the political sphere aims to create discourse between policy makers and the public, as a form of "legitimation of political ideas to the general public" (Schmidt 310). Members of this sphere may be political actors, the media, community leaders, social activists, intellectuals, experts, think tanks, social movements, but most importantly civil society. Through this sphere citizens have a chance to communicate their concerns and give way to deliberation. Communication may take the form of grass-roots movements, social mobilization and demonstration; by forming their own "mini-public". The thesis questions this approach, in accordance with several esteemed authors. At the forefront of this opposing viewpoint, Schmidt questions the traditional 'top-down' interaction of policy-makers and the public. The 'master discourse' is no longer inflamed by the political elite, but by the civilians themselves. The evolution of a "bourgeois public sphere" (Habermas 1962) may be on its way. Therefore, the thesis believes that a new form of 'bottom-up' governance has begun to enter the discourse on institutional-civilian interaction. This process may already be observable in the topic of civilian initiated health care reform through the instrument of patient empowerment.

The latter theory fits perfectly with the thesis' assumptions; through the popularization of active patient communities and advocacy groups, the EU as an institution was pressured to the point of joining the discourse of patient empowerment and gradually initiated policy change. Thus, this caused the EU to shift its institutional discourse within the topic of patient care. This ‘bottom up’ approach to policy-making may be observed in one of the earliest and most influential patients’ rights documents, the Amsterdam Declaration in 1952. The declaration states that “social, economic, cultural, ethical and political developments have given rise to a movement in Europe towards the fuller elaboration and fulfilment of the rights of patients” (WHO 5). Discursive institutionalism is also a theory that is increasingly applicable to modern organizational patterns. Due to the massive impact of information flow surrounding us, people are able to organize around an issue more swiftly than ever before. Not only due to the rapidity of establishing connections and communication through social media, but because the information asymmetry amongst policy-makers and civilians has begun to even out. We, as informed citizens, have the necessary tools to research regulations and the implications those may have on us. Consequently, the media has become a stronger and more informed force and has affected the shift from ‘top-down’ leadership to a more flat and horizontal societal structure. One such example of informed citizens (in this case patients) having significant influence upon policy-makers was in Italy (2003) when Italians protested against government restrictions on banning genetic screening of embryos for diseases, such as cystic fibrosis. Costa and Pavan, an Italian couple, were both healthy carriers of cystic fibrosis thus wanted to screen there embryos to see if their disease had been passed on, before starting in vitro fertilization. The Italian government argued that the legalization of pre-birth genetic screening would give way to eugenic thinking and ‘designer babies’. Thus, the Italian government denied their plea for genetic screening. Consequently, their daughter was born with the disease in 2006 (ECHR 327). This caused a massive uproar and eventually reached the European Court of Human Rights (ECHR) in February 2013. The ECHR found the Italian regulation a violation of right to privacy and family life, as well as a violation of fundamental health and freedom of research rights (Donovan 2014). The Italian government had to pay €17,500 in damages and expenses to the couple, as well as repealed the ruling and has given right for both sterile and fertile couples to genetically screen their embryos. Thus, through the couples demand for empowerment, in the sense of being provided the opportunity for information about their health care conditions, changed national legislation. What is more, it also affected the reproduction rights movements strive for accessible bio-data concerning heavily invasive treatments such as IVF and Intracytoplasmic Sperm Injection (ICSI).

Based on Dryzek's "Deliberative Democracy" model, I believe that through the implementation of patient empowerment legislation into legally binding EU health care legislation, the EU might achieve the democratization of health care. Naturally, the implementation of empowerment also covers a wide array of scholarship. One of its paramount representatives was the study conducted by Lopes et al. on the effectuation of gender empowerment within Portuguese civil society. The research (2008) aimed out finding the effective means of institutions implementing empowerment though civil society organizations, such as NGOs. They concluded that "the current popularity of the concept of empowerment reflects the transformation from a top-down paradigm of change to another more participatory, bottom-up, in which the populations have a voice in development processes" (Lopes et al. 3). However, they too noticed the gap between institutions and civil society, due to the new European Union model of multilevel governance, representation is harder to achieve on the supranational level. Thus, unless national governments and their civil society do not decide to implement empowerment into their daily workings, such supranational guidelines as the EU Health Care Strategies will have no effect on internal change. "In civil society organizations we also observed too often a big distance from the political; a distance from the public sphere and broader societal concerns and the lack of inscription of their activities in the long-term and in the broader scales of the fights against discrimination, inequality and injustice" (Lopes et al. 18).

The research's contribution to the field would be its novelty by observing official EU rhetoric through qualitative analysis. Analyzing the actual discourse that has been taking place over the years, we may study the formation of the doctor-patient culture. While, many studies have been conducted on the topic of EU institutional discourse, healthcare strategies and patient empowerment, there has been none that merged all three aspects together. This is important in order to further develop the discourse between patients and institutions in order to establish successful and efficient policies that serve the health and interest of citizens. From a further perspective it is also imperative to observe the discursive shift in order to assess whether the theory of discursive institutionalism applies to contemporary policymaking. In sum, whether the citizens' voices have the right channels to be heard.

3. Background of Patient Empowerment

An additional definition of patient empowerment that the thesis was aided by is one devised by R.M. Anderson and Martha M. Funnell in their 2005 article titled Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. It states that patients should be seen as experts of their own body and of their own condition. Therefore all medical interactions should be a meeting of equals. The doctor is present as the expert on potential medical treatments the patient is present as an expert of her condition and state of health. Through this equal partnership patients will have the right to be active cooperators and will have more control over the management of their health care. Patient empowerment aims to aid patients in taking control of their health care through empowering them with information and medical decision-making.

What is apparent from the conducted research and reflected from the average patient-experience is the doubtful image of health care as a business; as industry. Concepts such as cost-efficiency and value enhancement have become key-words in health care policy-making, especially when observing the latest EU Commission Health Care Strategy of 2014-2020. Health has officially become business; an industry. Patients are viewed as consumers and are thus evaluated within a ‘costs and benefits’ system, by measuring the amount of pharmaceuticals one consumes, the amount of time and attention patients receive by medical professionals, insurance costs, etc. Hence, when observing the reasons behind patient’s distrust of the health institution, we may simultaneously study why the ‘consumer’ distrusts ‘the industry’.

As Nicholas Brody points out in his article *The Rise of the Empowered Patient*, published in the Scientific American, one may pin the spark of the patient empowerment movement to two main elements of the modern health care system.

One of the most obvious reasons behind this aforementioned 'slip' is the price of health care, especially the price of pharmaceuticals. Although many European Union member states may maintain universal health care systems, the price of medication still remains a challenge for patients. With the constant patent litigation conflicts between private and generic drug companies, rising costs are collateral to be considered. In addition to elongated research and development processes (which may take up to 10-15 years and up to $80 billion), which are constantly paused due to infringement accusations, pharmaceutical prices are bound to rise. Therefore, people simply cannot afford to not know why they are prescribed a certain type of medicine; they cannot afford to engage in a "trial and error" sort of medical care. Because patient's trust comes at such a high price, it is in the interest of the industry to adhere to their 'demands' in order to maintain a well-functioning health care system. Consequently, patients have begun to demand their bio-data in order to see the real-world outcome of their medications.

The second driving force behind the recently developed patient movement is the prevalence of unsafe drugs. With the recent emergence of "rogue wholesale drug distributors selling potentially unsafe drugs" (FDA) patients are becoming more and more skeptical of medical advice and of prescription drugs; due to the fact that many medical professionals are provided incentives from certain drug companies in exchange for writing prescriptions that benefit their products. For example, the Vioxx crisis in the U.S., which was an Arthritis drug launched in 1999 and consumed by millions, had to be withdrawn from the market in 2004 because of increased risk of heart disease due to regular drug consumption. The recall of Vioxx cause huge societal uproar and led to further distrust. Furthermore, it led to the distrust of the medical regulating agencies as well. In the case of Vioxx, U.S. federal agency of the Food and Drug Administration agency went through a huge public relations crisis due to their massive oversight of the drug. Approximately, 1.5 million people are injured every year due to the consumption of unsafe drugs (Brody 2). According to the Center for Disease Control's New Health Report (2010) 70% of patients feel as though they have no effect on the type of drugs currently being released into the market. Consequently, many choose to take matters into their own hands and consult patient communities, diagnose and monitor themselves, consult alternative medicine, and overall turn away from institutionalized medicine. Patients are no longer "passive consumers", but rather "choosy consumers" (Brody 1). People have become "expert patients" that is, "those who can manage their own illnesses and conditions by developing knowledge relevant to maintaining health and countering illness" (Shaw and Baker 2004). Background of Patient Empowerment

The definition of patient empowerment that the thesis was guided by is one devised by R.M. Anderson and Martha M. Funnell in their 2005 article titled Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. It states that patients should be seen as experts of their own body and of their own condition. Therefore all medical interactions should be a meeting of equals. The doctor is present as the expert on potential medical treatments the patient is present as an expert of her condition and state of health. Through this equal partnership patients will have the right to be active cooperators and will have more control over the management of their health care. Patient empowerment aims to aid patients in taking control of their health care through empowering them with information and medical decision-making.

What is apparent from the conducted research and reflected from the average patient-experience is the doubtful image of health care as a business; as industry. Concepts such as cost-efficiency and value enhancement have become key-words in health care policy-making, especially when observing the latest EU Commission Health Care Strategy of 2014-2020. Health has officially become business; an industry. Patients are viewed as consumers and are thus evaluated within a ‘costs and benefits’ system, by measuring the amount of pharmaceuticals one consumes, the amount of time and attention patients receive by medical professionals, insurance costs, etc. Hence, when observing the reasons behind patient’s distrust of the health institution, we may simultaneously study why the ‘consumer’ distrusts ‘the industry’.

As Nicholas Brody points out in his article The Rise of the Empowered Patient, published in the Scientific American, one may pin the spark of the patient empowerment movement to two main elements of the modern health care system.

One of the most obvious reasons behind this aforementioned ‘slip’ is the price of health care, especially the price of pharmaceuticals. Although many European Union member states may maintain universal health care systems, the price of medication still remains a challenge for patients. With the constant patent litigation conflicts between private and generic drug companies, rising costs are collateral to be considered. In addition to elongated research and development processes (which may take up to 10-15 years and up to $80 billion), which are constantly paused due to infringement accusations, pharmaceutical prices are bound to rise. Therefore, people simply cannot afford to not know why they are prescribed a certain type of medicine; they cannot afford to engage in a “trial and error” sort of medical care. Because patient’s trust comes at such a high price, it is in the interest of the industry to adhere to their ‘demands’ in order to maintain a well-functioning health care system. Consequently, patients have begun to demand their bio-data in order to see the real-world outcome of their medications.

The second driving force behind the recently developed patient movement is the prevalence of unsafe drugs. With the recent emergence of “rogue wholesale drug distributors selling potentially unsafe drugs” (FDA) patients are becoming more and more skeptical of medical advice and of prescription drugs; due to the fact that many medical professionals are provided incentives from certain drug companies in exchange for writing prescriptions that benefit their products. For example, the Vioxx crisis in the U.S., which was an Arthritis drug launched in 1999 and consumed by millions, had to be withdrawn from the market in 2004 because of increased risk of heart disease due to regular drug consumption. The recall of Vioxx caused huge societal uproar and led to further institutional distrust. Furthermore, it led to the distrust of the medical regulating agencies as well. In the case of Vioxx, U.S. federal agency of the Food and Drug Administration agency went through a huge public relations crisis due to their massive oversight of the drug. Approximately, 1.5 million people are injured every year due to the consumption of unsafe drugs (Brody 2). According to the Center for Disease Control’s New Health Report (2010) 70% of patients feel as though they have no effect on the type of drugs currently being released into the market. Consequently, many choose to take matters into their own hands and consult patient communities, diagnose and monitor themselves, consult alternative medicine, and overall turn away from institutionalized medicine. Patients are no longer “passive consumers”, but rather “choosy consumers” (Brody 1). People have become “expert patients” that is, “those who can manage their own illnesses and conditions by developing knowledge relevant to maintaining health and countering illness” (Shaw and Baker 2004).

4. Human rights, Patients' Rights

Health and human rights have been proven to be inner-linked concepts with the common goal to advance human well-being (Mann et al. 16). Furthermore, they may also be in a cause-effect relationship towards one another, because the violation of human rights will have health implications. The human rights movement has a rich history to look back upon, beginning from the 1945 United Nations agreement, which stated that "all people are born free and equal in dignity and rights". Later this was fortified by the 1948 Universal Declaration of Human Rights and was adopted as a common standard for all peoples and all nations (Mann et al 17). Naturally, these were followed by an abundance of regulations to come, adopted both on national and supranational levels. Gradually, human rights documents began to expand their boundaries and incorporate public health into its areas of oversight. Patients' rights have seen an increasing development in importance since the beginning of the 1940s, especially after the end of the Cold War and at the beginning of the 1980s when the HIV/AIDS epidemic hit. Sexual and reproductive health concerns were the flag barriers for the modern framework of human and patients' rights (Gruskin et al.). However, one of the most significant milestones in its evolution was the 1994 Amsterdam Declaration (A Declaration on the Promotion of Patients' Rights in Europe). The Declaration was constructed by the World Health Organization and the Dutch Ministry of Health (i.e. the Government of the Netherlands). It was drafted with the distinct purpose to further "full implementation of the concept of respect for persons and to equity in health as a policy objective in Member States" (WHO 5). Further, the Declaration was drafted to counteract some of the most burning issues of European health care, such as its structural complexity, its impersonal tone, increased bureaucratic tendencies, as well as react to the many medical and biotechnological developments that have changed how patients face medicine and healing. However, one of the most substantial reasons for the Declarations creation was the demand of the people to better understand medical policymaking. Although, many of these demands were voiced towards chronic illnesses, cancer or HIV/AIDS rather than change general patient care. No wonder that some of the first European Union health care action groups were formed around these specific ‘patient interests’. It is important to mention that the text differentiates between social rights and individual rights. As does modern human rights between public health and individual medicine. While public health emphasizes the health of populations, medicine is more concentrated on the health of the individual. The same division of concepts may be observed between social and patient interests. Social rights relate to the “societal obligations undertaken or otherwise enforced by government and other public or private bodies to make reasonable provision of health care for the whole population” (WHO 6). Meanwhile, individual rights are more focused on private health care needs and “can be made enforceable on behalf of an individual patient” (WHO 6).

Noted as one of the most impactful documents, the Oviedo Convention (Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine) of 1997 introduced some of the most groundbreaking ideas health and biotechnology policymaking. Not only because of its cutting edge content on biomedical human rights issues, but also because this was the first ever example of a piece of transnational legislation. Certain regulations and “soft laws” had existed beforehand, but a “hard law”, i.e. a legally binding, promotion of health had not (Adorno 133). It was also the first treaty that addressed the linkage between human rights and biomedicine. It was drafted by the European Council in 1997 and entered into force in the December of 1999. It was a document that was signed by 31 countries and ratified by 19. The Oviedo Convention is used as a sort of “framework instrument” by modern policy-makers, it provides general principles, yet it still leaves room for Member States to enforce stricter rules concerning certain topics. In addition, the Convention contains some of the most essential regulations on the rights of patients, such as informed consent, private life and right to information and scientific research. Informed consent is vital to ensure the rights of patients to individual autonomy. Medical intervention carried out without permission is (under Article 5) is strictly prohibited. The issues regarding the right to private life and right to information address the right of the individual to know (or sometimes not to know) about their treatment and/or medical condition. Lastly, the issue of scientific research is an extremely important factor in the fight for furthering the rights of patients due to the fact that there are still several Member States that restrict the right to better understand a person’s medical condition through genetic testing. This, article was explicitly referred to during the Italian in vitro case, when the Italian government restricted the right of couples undergoing IVF treatment to genetically test their embryos for diseases, by arguing that genetic testing gives way to eugenics. As prior states, this was later overruled by the European court as unconstitutional.

5. EU Health Care

Currently, EU health care policy-making faces a number of issues; these primarily manifest themselves on its macro as well as micro levels. Firstly, on the macro level, one may observe the lack of uniformity amongst Member States' national health care systems. Consequently to this incongruence, no shared funding systems have been developed amongst the 28 Member States. Despite most systems being funded primarily through taxes and provided on a universal basis, many Europeans are facing increasing out-of-pocket expenses. This incremental increase is closely tied to the rising prices of pharmaceuticals as well as a decrease in quality of public health institutions. This has created a gradual transition of citizens turning away from the state-owned medical facilities and to private medical care. Through the increasing numbers of patients receiving treatment outside of their home country (cross-border), as well as substantial amounts of clinical staff members migrating to other EU countries, transnational health care legislation has become an issue to be dealt with.

Additionally, the drastic aging of populations has grown into a problem in almost all EU Member States and has given way to great anxiety to future health policy-making and labor market dynamics. Increased longevity of EU citizens, utilization of health care services, and prevalence of chronic disease care and illnesses are all current symptoms of the aging EU society. Accordingly, the time devoted to doctor-patient communication has been elongated and will continue to do so in the future, forcing patient empowerment to take a pivotal stance in everyday medical interaction.

Interestingly enough, the European Union does not take on any critical administrative role, or responsibility, in the field of health care. The European Commission, specifically the Directorate

General for Health and Consumers, seeks to align national health care laws and aims to create a more synchronized system amongst the member states.

Both national and European Union health care have to face the simultaneous pressures of ever-decreasing health care funding but increasing demand for quality patient care. The European Union health care system has been witnessing a gradual decrease in its funding and is becoming more heavily reliant on cost-efficient ways of improving patient-care. Furthermore, costs are incrementally increasing due to higher costs associated with research and development as a result of copious patent infringement cases between pharmaceutical companies. Therefore, the healthcare system is facing a deadlock of reduced funding, due to shrinking populations, but increasing demand and increasing cost. Because of this volatile course of EU health care and demographics, many officials believe that patient empowerment would not be an efficient solution to the problem. The costly one-on-one nature of shared-decision making and presenting additional treatment options to patients has frightened decision makers. Moreover, the medical consultations undertaken in this manner would take up significantly more time, thus further raising costs and diluting efficiency.

There is a clearly outlined approach of cost-efficiency recognizable within the 2014-2020 EU Commission Health Strategy. The Strategy emphasizes the need for time preservation within medical visits, surgeries and rehabilitation. Thus, it encourages hospitals to offer more outpatient options for patients, pursuing less face time with doctors onsite. Furthermore, it encourages the cutback of medical specialists and instead promotes the training of a larger set of general practitioners. The intention here is to increase capacity for medical consultations and reducing specialized counterparts, who are less versatile. Patient empowerment in this context takes on a very different form than of previous health care strategies; more on this in later chapters. Here, it is seen as a tool to, essentially, ‘keep patients out’ of hospitals and all other medical institutions. If a patient is able to diagnose and treat herself in her own home, she will be encouraged to do so.

Contrary to the EU Commission’s belief, studies done by: the Society of Participatory Medicine, show that patient empowerment actually amounts to better health outcomes, lower medical costs and improved efficiency. Because patients are encouraged to participate in their own betterment, they have incentive to improve their knowledge about their condition. Hence, when they attend consultation with their doctors the dialogue becomes a two-way exchange of medical options. Consequently, working in favor of timeliness and efficiency; according to the National Healthcare Quality Report (2009), the presence of shared-decision making and patient empowerment improved patients’ overall health status, lessened the burden of symptoms and lessened the chance of misdiagnosis (Brody 3). Many have dubbed this new movement as Health 2.0. There is also a very strong beneficial psychological element connected to the effects of patient empowerment, mainly comprised of the sense of community and belonging. This shared sense of community results in patients feeling as though they are taking on responsibility before their peers, thus becoming accountable for their self-betterment.

Unfortunately, the economic benefits of patient empowerment are often neglected. This is particularly pivotal when discussing the containment pressures of EU health care; on one hand one may observe an ever-increasing consumer demand on the patients’ side, whilst on the other hand witnessing the gradual decrease of health care funding. However, the market aims to meet consumer demands; and thus, by meeting the needs of consumers, through effective and empowered communication, policy makers are able to ensure that the market is driven by consumer preference. By adapting to this service delivery model (Segal 42), empowerment may provide for a more cost-effective system.

Finally, the decentralization of health care may also add to the possible solution of empowerment. Through enabling regional health care oversight, communities would have a chance to better communicate demands. Thus, health care concerns could be mirrored within a faster response time by policy-makers.

6. Individualized medicine

Referring back to the conflicting interests of pharmaceutical companies and the patient empowerment movement, there has been a plethora of exciting new developments in the field of pharmaceuticals that are essentially aimed at the individual empowerment of patients. On account of people demanding more specialized care; more specialized medicine; pharmaceutical companies have begun experimentation with a new branch of biotechnology, so called Pharmacogenomics. Pharmacogenomics aims at producing and supplying patients with medicine based on their genetic make-up in order to maximize efficiency, thus a new era of "personalized medicine" may dawn upon us. This development will be vital to be patients suffering from chronic diseases. By understanding their genetic consistency, doctors will not only be able to treat symptoms but to actually heal the patient.

Conversely, the evolvement of patient empowerment has to be a two-way street. Thus, patients themselves have to implement advancements in viewing and treating sickness. In order to maximize efficiency for consultations, patients have to independently conduct research about their conditions, if not through a strictly medical lens, but in a manner of self-monitoring.

In summary, the most crucial issue for health care to address is that of information asymmetry. This asymmetry is prevalent between doctors and patients, between pharmaceutical companies and consumers, the biotechnology industry and health care. Most importantly, this asymmetry is prevalent between the institution and the patient. Fortunately, the Internet has already started the process of balancing out these uneven distributions. The internet has begun enabling patients to conduct research on their conditions, medications, find likeminded communities, search for alternative options, and monitor their progress. This is an ever-expanding process and numerous hospitals and medical facilities have started to engage in multimedia- and social platforms in order to better engage with their patients. For example, some hospitals started utilizing Twitter, to "tweet", their surgeries, to provide patients with the kind of health care service they want; a service that is 24/7. On the platform side, a popular patient empowerment website named Save the Patient has recently partnered up with a software company in order to develop special flash drives on which patients can store their medical data. Hence, when they visit a medical facility all their data will be with them and their health care providers will be able to go back in their patient history without having to consult several files and by risking an information gap.

There are certain particular repercussions of the type of consultations patients engage in via the Internet. Overall, the Internet has served as a great tool in the hands of uninformed patients who desperately want to understand their condition and treatment options. However, sometimes within this uniformed desperation, the patient's autonomy can lead to starting a process of self-medication which in some cases has proven to be fatal. It is vital to understand that patient empowerment has to be a two-way process and requires dedication from both the institutional, doctor side and consumer, patient side. Thus, all medical information should be run by a medical professional. Nonetheless, many patients will swap information or read about alternative treatments that helped others, and try to self-administer the same therapy. Often, only to find out that the differences in their conditions leading to a therapy that is ineffective, or worse, detrimental to their health state. Consequently, patients need to follow the directions of their physicians, who understand the complex drug regimens their patients have had to endure in the past and how those chemicals will affect another. These directions may be a result of a prior agreement through the shared-decision model, but patients have to adhere to certain treatment processes.

Another one of the significant points on the European Union health care agenda is the issue of EU cross-border care. The EU states that patients have the right to consult with any physician of their choosing, including any working in EU Member Nations. Furthermore, they have a right be reimbursed for their care. According to EU law, patients will receive equal treatment opportunities as well as urgency in any cross-border facility of their choosing.

Currently, the European Union is facing an immense amount of issues, both political and economic, that will ultimately affect the patient community in later years. Economic factors, such as the recovery from the recent financial crisis have set many EU member states back in their path to empower patients. Furthermore, it also gave way to even bigger gaps amongst member states concerning quality medical attention, as well as quality medical personnel. Naturally, this tendency has taken its toll on national health care budgets all across Europe, especially when one takes into consideration the previously discussed rising pharmaceutical costs. Another significant issue waiting to be resolved is the problem of an aging population in Europe. “People aged 65 and over are the fastest growing segment of the population, and this age group is projected to grow to more than 25% of the total population of the European region by 2050” (McKee 2010). People are also living longer, what is more people with chronic diseases have also developed in longevity. Thus, medical facilities are seeing a rise in chronic patient care and have to invest in medical tools, pharmaceuticals and staff equipped to treat people with long-term health problems. These trends are in constant clash with the pressure that member states are facing to cut health care costs and initiate cost-benefit assessments (EPF Strategy).

Prevalent political factors in current EU health care are mainly concerned with the issue of not being united. Because health care is seen as a federal level issue there has not been a developed practice other than certain strategies that are unenforceable and not legally binding. Thus, there is no best or worst system to follow, especially due to the many inequalities amongst member states, which is further amplified by the recent migration of health professionals across the EU. However, what is the most urgent political issue within the EU patient empowerment discussion is matter of how to solve the information gap between the EU as an institution (i.e. policymakers) and patients' needs. "Patients' rights are established and patient organizations set up and strengthened in many Member Stats. Finally, patient involvement in policy-making is still controversial and there is a gap between the EU and national level in the extent to which patients and patient organizations are involved in high-related policies" (EPF 9).

6.1.Implementing empowerment

The Euro Health Consumer Index is an open assessment conducted by the Health Consumer Powerhouse of European patient empowerment. It too, realizes the strain put on the European Union of having to balance increased demand and increased medical costs, within a highly indebted system. The Index also ranks countries based on how well their patient empowerment mechanisms work within their respective health care systems. Evaluations are based on the assessment of patient rights, patient access to his/her data and financial medical incentives. These points of evaluations are then transferred onto a scale maximum 1000 points. The top three ranking countries are the Netherlands (898 points), Switzerland (855 point) and Norway (851 points). So the question of

Successful implementation of patient empowerment is heavily dependent upon its reception in civil society. There has been a shift from government to governance, as a Portuguese study on gender equality concluded (Lopes et al 2008); the population has gained voice in the process of decision-making. Within their study, Lopes et al. chose to study the relationship between civil society and government within the realm of gender equality in Portugal. The research observed that through the technical governmental support of NGOs who were already active in their role as gender equality advocates, the state was able to deepen the effect of the policies. Lopes et al. describes this process as a “co-constructive dynamic” between state and civil society. One of the main modes of measuring this shift in governance, that the research utilized, was researching the degree of empowerment these gender equality advocate NGOs held within their communities. This, they did through observing internal and external accountability, community assimilation, participatory mechanisms, strength of networks and political activities. They found that empowerment was an exceptionally useful tool in our present era of multi-level governance, i.e. ranging from supra-national (EU representation), to national and finally to local levels of governance. Its effectiveness may be explained by its necessity to open up negotiation and dialogue between the public and decision-makers. Ultimately, it put into effect the goal of empowerment which aims to give voice to the people in order to shape policy-making.

In her article, Segal identifies six key points that must be addressed in order for a government to implement successful patient empowerment into its national health care model. Firstly, the information asymmetry between clinicians and patients must be evened out. Consumers have to be given an option to become ‘informed patients’. Secondly, to further the quality of information for patients, the promotion of health education must become a priority. Subsequently, Segal suggests the training of governmental agencies, NGOs and independent providers to encourage empowerment and to promote patient-centered communication. This, I believe will become cardinal in future implementation efforts, as it will serve as a bridge between institutions and patients by mediating between the two parties. Thus, as a fourth point, the mechanisms to induce communication between these agencies and patient communities must also be developed. This also implies that the role of agency will have to be defined in the future in order to structure the use of empowerment. Lastly, the health care budget must be structured in a more transparent way that will allow for more individual and community control of health. Above all, patient empowerment must be named as an explicit objective; its development, implementation and popularization have to become a priority.

6.2.e-Health Initiative

One of the most recent developments within EU health care has been the e-Health initiative; an all-encompassing EU e-health project. The development of the eHealth initiative has been a direct response to the current tendency of patients turning away from institutional medicine and rather searching for answers through self-monitoring devices-, websites, and technology. Thus, eHealth has become a direct counterpart of the several emerging online patient communities and monitoring systems for patients to keep track of their bio-data as well as their medical progress. This is also a method of the EU to demonstrate its intention of implementing preliminary health care reforms. The e-Health project is aimed at “helping free movement of patients, and improve access to quality care in remote or underserved areas” (O’Donell). Through eHealth, patients will be able to freely access their personal bio-data, retain control over their medical data, and personalize health monitoring devices. Personalized medicine is already a major driving force behind biotechnology and computer science innovation, especially the development of non-invasive monitoring devices. Having personalized medicine will strengthen some aspects of patient empowerment, such as having control over one’s data or being able to research medical options. Nonetheless, these innovations will not be a direct replacement for efficient doctor-patient relationships. They will not present an adequate solution to the communication gap between institutional health care decision-making and the actual consumer interests of patients. Research conducted shows a qualitative meta-review of e-health implementation studies conducted by Mair et al. (WHO 2011), this found that there has been growing emphasis on the many problems related to e-health systems. These problems were related to e-health's lack of addressing important issues such as 'roles and responsibilities', 'risk management', 'ways to engage with professionals', 'ongoing evaluation and feedback of new technologies and treatments' (Mair et al. 2011). Thus, it becomes apparent that the e-Health initiative is far from being the solution the EU has perceived it to be.

7. Research

On the basis of the findings of prior inner-research conducted on the issue of patient empowerment in the European Union the thesis was able to validate its assumptions of patient empowerment in official EU rhetoric. Namely, patients have wandered so far from institutionalized medicine because of the information asymmetry between health care institutions and patients that they eventually turned towards their own communities and have started to demand patient-centered care, to the point that there had to be an institutionalized response. Alongside the development of patients' rights, the various health care movements and the emergence of self-monitoring technology, patient empowerment became an unavoidable pressure that institutions are faced with. Consequently, the thesis aims to observe the patterns of EU institutional reaction towards the changes taking place in patient communities. It did so with the aid of qualitative research, more specifically frame and thematic analysis.

Drawing on the theory of discursive institutionalism, patient empowerment became an issue discussed in the institutional setting due to the voices of civil society (activists, advocacy networks, individuals, etc.). Thus, I argue that patient empowerment evolved into a grass-roots movement that has begun to shape institutionalism into a more patient-centered health care system. In order to monitor this change, I decided to research the change in themes in which patient empowerment has been framed within EU institutional rhetoric. Due to the recent popularization of such aforementioned patient empowerment efforts, the preliminary assumption of the research was to find patient empowerment in an increasingly prominent position with the progression of time.

The data was collected from the online archives of the EU Commission. Due to the many internal changes the organization went through the earlier documents were difficult to trace, especially during the period of 1996-2002, when public health care was under the supervision of 8 Action Groups, overseen by the Directorate General (DG) of Health. The group that was in charge of consumer-agency interaction was the Action Group for the Promotion of Public Health, thus I decided to only take into consideration their documents.

It is important to mention that two of the health care strategies (2008-2013 and 2003-2008) had evaluation reports published about their programs. I could not include this in my research for three reasons. Firstly, because the evaluations were only applied to 2 out of the 4 documents examined. Furthermore, meanwhile one is a mid-term evaluation (2008-2013), the other is an ex-post evaluation (2003-2008). Thus, it would not have given me an overview of the same period. Finally, the evaluations assess the progress of the programs achieved so far, thus it is highly repetitive of the document itself as well not representative of official EU strategic discourse.

7.1.Data

The reason behind the choice of EU Commission health care strategies was that these documents are intended to provide a future framework (usually for a number of years to come) for all member states, though not legally binding. They are meant as general guidelines to be followed, as well as contain a series of future public health policy suggestions with the hope of triggering policy change in the member states. The current strategy always replaces the ones previously issued hence there are a number of overlaps between the programs. Certain topics, such as inequality amongst member states or health care education, are always reiterated.

The data consisted of four official EU Commission documents. These documents are all health care strategies (earlier documents are named Programs) that the EU issued from 1996 up until

2020. The timeline of the data is as follows: 2014-2020, 2008-2013, 2003-2008, and 1996-2000 (with a prolongation of the strategy till 2002, thus the addition of the time period of 2001-2002).

The scope of the data is a period of 24 years, which was divided into 12 and 12, in order to adequately assess and compare the development of EU health rhetoric. The 2003 establishment of the EPF, as aforementioned, was the dividing point between the 12-12 years. Thus, the 4 documents are divided into two groups; pre-2003 and post-2003 periods. Within the pre-2003 group there were 2 plus 1 documents analyzed, meanwhile in the post-2003 group there were two documents studied. At first glance, the divide might seem unequal, however oversight of EU public health went through a number changes. From 1993-2002 EU public health care was under the management of the Directorate General. During DG supervision, health care was divided up into 8 ‘action programs’ consisting of public health promotion, combatting cancer, AIDS prevention, prevention of drug dependence, health monitoring, injury prevention, raise awareness of rare diseases, and pollution related diseases (of which I chose one specific action program). These action programs were meant to monitor all sub-fields of public health. During this period the Promotion for Public Health Action Group produced a number of 2 documents; of which the first one was for a 4 year cycle from 1996-2000. The Group prolonged their 1996-2000 health program to be in effect for the year of 2001-2002 as well. Thus, essentially it is an extension of the previous program. The reason for this appeal was that the health care sector was already under structural alterations and during the next couple of years it was bound to change leadership. In 2002, the action groups were merged into 1 main organization, who drafted the new health program in effect from 2003 till 2008. After 2002, the merged action programs melted into the EU Commission. The last two health care strategies undertake a time period of 12 years, with the official health care strategy cycles being extended to 6 years. Hence, these documents; 2008-2013 and 2014-2020 will embrace the same amount of time.

Because of the many structural changes of supervision and content the texts differ in styles and layout. One may observe that the earlier programs refer much more extensively to groundwork legalities, hence they extensively cite EU laws and memorandums. Meanwhile, the later strategies are written in a much more fluent language and designed in a way to attract readership. Thus, I am also certain that the purpose of these programs changed over the years as well. The earlier programs were distributed and meant for the inner EU policymaker circle, whilst the later ones are more like advertisements of that specific health care legislation cycle. For example, in the earlier versions of the programs the text makes specific references to countries that are in waiting to become member states of the European Union, as well as providing aid to countries that are in close alliance with the EU, such as Cyprus or Turkey. The texts changed in length as well; the first texts are only 5-10 pages, but the later (2008-2013, 2014-2020) range from 20-25 pages. As aforementioned, they also differ in voice and target audience; as time progresses, we may observe a more familiar tone with a more market driven attitude. The language also became less technocratic and more understandable to people that are not professionals of the medical policy field. Furthermore, not all of them bare titles either, this is more characteristic of the newer versions. One may further observe that the latest strategy of 2014-2020, titled *Investing in Health,* has been widely marketed on the official EU health policy website. Hence, I speculate that the target audience is no longer just policymakers, but also the health care community and the general populace, which may add to the fact that more and more EU citizens are becoming interested in the future of EU health care legislation.

7.2.Method

The goal of the research was to study the discursive shifts that went into effect during the 24 year period of European Union health care strategies. In this manner, I decided to utilize the qualitative method of thematic analysis as well as frame analysis and study the 'shifts' in the 4 compiled EU Commission health care strategies. Through frame analysis one is truly able to see beyond the curtains and assess the different definitions that patient empowerment has underwent. Concurrently, thematic analysis was used in order to emphasize certain patterns within the documents.

The research focused on one aspect of the four texts; patient empowerment. Thus, the chosen categories for the thematic analysis all correspond to the same theme of patient-centered rhetoric. The chosen themes were as follows: participation/access, empowerment, inequality, and monitoring.

Participation was chosen as a theme in order to analyze, the sort of involvement these documents encourage. For example, while some texts emphasize 'member state participation', others distinctly point out the need for 'patient participation'. Thus, I deemed it pertinent to the research to see how, metaphorically, inviting these documents are to the reader. Access was an additionally eminent concept to take into consideration in connection with participation. A patient's access to her medical records and sharing information with her doctor is one of the founding concepts of patient empowerment. The medical community has to find a way back to its patients, the solution lies in free information sharing. Patients have to be given a chance to communicate their feelings and health statuses without guilt or shame to their physicians, in return doctor themselves have to face the consequences of giving out more medical information. , “Some physicians are often reluctant to disclose information relevant to making uncertain choices” (Frosch, Kaplan 289).

Empowerment was also included within the themes, due to it being the principal topic for the research. However, analyzing the different framings of empowerment was a very important aspect of the paper. All of the documents have a different idea of what empowerment is, therefore contextualize it in a different matter. In some texts, empowerment takes on the meaning of patient protection (i.e. protection from bad health care), while in others empowerment is more of a psychological state of feeling confident and enabled to care about one’s own condition.

Inequality, I found was important to include within the list of themes, although it may seem as an outlier. In the more general usages, inequality is mentioned in the context of ‘inequality amongst member states’, which subsequently affects the differing levels of quality health care from one member state to another. Therefore, also having an impact on inequality between patients and the type of medical care they receive. Furthermore, many of the texts refer to enabling member states with low quality healthcare and providing them with additional funds in order to bridge the gap between other nations; hence, providing a service of empowerment to these states.

Finally, the theme of ‘monitoring’ is also an important concept within the analysis, due to the fact that patients like to know that the system is accountable and enforcable. Through having a sort of inner monitoring institution or agency within health care, patients feel as though their interests are prevailing without their presence. This is why EU organizations such as the EPF were not only important in future medical policy making but also for the patient community to know that their interests have some sort of representation and accountability within the system.

In order to gain a larger perspective of the research I decided to do two types of readings of the data. First, I read the data without any comparative aspect, i.e. without taking into consideration the 2003 (EPF establishment) dividing point, but rather just reading the texts one after the other. This was helpful in determining the differences between framings of meanings, such as the different definitions of empowerment utilized in the different texts. Second, I placed the comparative aspect to the forefront of my analysis, in order to compare and contrast the presence of patient center care in the pre-2003 era and the post-2003 period.

8. Findings

8.1.Frame Analysis

Through the first method of analysis, i.e. analyzing the texts all in one, without divide, I was able to pin down differences in the framing of empowerment. In the first text (1996-2000), empowerment is seen as enabling patients to have better control over their health through health education and advocating for a healthy lifestyle. The program's objective is "to improve knowledge of mechanisms for devising health messages and assessing health information methods and encourage an exchange of information and documentation between professionals and those responsible for public health and health promotion policies." (EU Health Program, 1996-2000). Subsequently, in the second text the rhetoric shifts from health education to 'health protection', within the context of empowerment. Health protection is seen as a way for citizens to receive sound information concerning their condition (as is one of the prerequisites of empowerment) in order to successfully avoid infection or disease. "In this framework, attention should be given to the right of the Community to receive simple, clear and scientifically sound information about measures to protect health and prevent diseases, with a view to improving quality of life." (EU Health Program 2003-2008). The third program is the one that concentrates the most heavily on patient empowerment, going as far as declaring it a right of every citizen. "Health policy should provide mechanisms and support for citizens to acquire the necessary knowledge and competences to enable them to act effectively in the interests of their own health and that of their families and communities, both in their everyday lives at home, work and school as well as when they are using the healthcare system." (EU Health Program 2008-2013). We may see that the Program's definition of empowerment is almost identical to the one referred to in the introduction of this essay by Funnel and Anderson. We may also go on to observe that social understanding is a very salient part of the 2008-2013 Program, ranging from the civilian level to high politics, spelled out in almost 6 pages of strategy. To my surprise, the newest EU health strategy of 2014 to 2020 takes a contrasting approach. Meanwhile, the previous program took a very open approach to empowerment and dedicated a whole section to its discussion within the text, the latest version chose to address it in barely one page. Furthermore, it's understanding of empowerment is framed in a mildly skeptical manner; "The idea of patient empowerment is often considered an important and promising aspect of chronic disease management, that can help people leader more proactive and fulfilling lives. Some evidence suggests that self-management can be effective through behavioral change, especially for people with long-term conditions" (EU Health Program 2014-2020). Although, the concept of patient empowerment is addressed it is only discussed within the frame of chronic and long-term diseases, leaving the 'social' aspects of empowerment out of consideration. The text actually goes on to refer to empowerment as the "practical understanding of patient empowerment", implying that there were certain redundant elements to it in the past, and relates it investing in research that studies "the effects of health investments on employability".

We may observe the framing practices of the texts in the following:

- 1996-2000 → empowerment through health education, advocating a healthy lifestyle
- 2003-2008 →empowerment through ‘health protection’
- 2008-2013 →empowerment as a right, emphasis on social understanding
- 2014-2020 →”practical understanding of patient empowerment”

In sum, we may observe an alternating tendency of positive patient empowerment rhetoric within the texts. The last two texts (2008-2013 and 2014-2020) have the sharpest distinctions in the topic of patient-centered care. On the on hand, the earlier text is almost overflowing with understanding of patient empowerment; it goes as far as including, patient communities and advocacy groups in its recommendation to construct a wider support net for civilians. Furthermore, it deems patient empowerment as a “core value” to European Union health care. Contrariwise, the latest version of the EU Health Strategy takes a distanced tone and suggests that patient empowerment is not “cost-effective” and “efficient” enough for EU health care, although it may help patient who are suffering from long-term diseases. Out of the four texts, I would say that the latest strategy is the harshest and most dismissive towards empowerment. This phenomenon came as a surprise as I assumed that the issue of empowerment was going to be a theme that would be emphasized more frequently as we went forward in time. Instead I would compare the latest health program to the one that was issues almost a decade ago in 2003-2008, where empowerment was contextualized within the frame of “patient protection”, i.e. a more “practical” understanding of patient care, where patients should be protected from bad quality health care. This may be achieved through protecting civilians from infections and diseases, that is to say, protect them from getting sick.

As aforementioned, I used the year 2003 as the dividing point between the texts, as this was the year the EPF was formed by the European Union. Hence, this was the year the EU decided to enter the institutional discourse on patient empowerment. There is a stark contrast between the pre-2003 and the post-2003 texts; firstly, the voices of the texts are utterly different. In the pre-2003 texts one may conclude that the documents were meant for policy-makers and EU legal professionals. This may be observed through the many technical words used as well as the various legal citations the documents contain. Furthermore, each document reiterates the points made by the previous one and only after does it make its own future policy suggestions. The post-2003 documents on the other hand were clearly written for a wider audience; there are barely any legal citations, longer pieces of writing and the terminology is understandable for people that are not EU professionals. Most importantly, the term ‘patient empowerment’ is only explicitly referred to, under a subheading, by the latest documents of 2008-2013 and 2014-2020. Although, the texts have extremely different understandings of the definition of patient empowerment, they are the only texts that outright address it. Meanwhile, the earlier versions of the EU programs merely mention the term and some of its synonyms such as “enabling through information” or “citizen participation”.

8.2. Thematic Analysis

8.2.1. Participation/Access

The pre-2003 texts address participation and access in the context of including non-member states in information sharing and public health cooperation, i.e. ensuring access for all European states to healthcare data and knowledge in order to bridge divides in quality (later referred to by the ‘inequality’ theme). The 1996-2000 text emphasizes the implementation of an “integrated approach" to health promotion, which was directed at raising awareness of health risks among all Europeans. This later (2003-2008 document) turned into invoking member states to actively participate in all EU health promotion matters in order to collect best practices and share their national experiences with each other. Thus, the program is asking for participation from member states in return for sharing the collected information for the betterment of the whole EU. Within the pre-2003 texts we may observe some overlap between the themes of 'access' and 'inequality', because of the texts focus on the inclusion of non-member states in healthcare related information sharing and cooperation, much of the theme of access is concerned with the issues revolving around access to quality healthcare for all, despite financial or ethnic background.

An interesting finding within this thematic analysis was that both post-2003 documents advocate for higher citizen participation and access to healthcare through 'e-health' and 'e-inclusion' technologies. Through these technologies citizens will be able to monitor their conditions and look into past treatments. Although, these are a long road ahead, the strategies see this as a potential method for increasing participation. Interestingly, both strategies address the issues of labor market participation, i.e. the lack of it, in connection with people suffering from chronic diseases.

8.2.2. Inequality

The theme of inequality was referred to in all 4 texts, mainly in the context of the varying levels of quality between member states when observing their healthcare systems. The pre-2003 texts frequently refer to aiding "non-member states" as well as providing channels of cooperation and information sharing. For example, the 2003-2008 document states that "the increasing differences in health status and health outcomes between and within Member States called for renewed and coordinated efforts at national and Community level" (EU Health Program 2003-2008). Thus, the objective of the program is “contribute towards the attainment of a high level of physical and mental health and well-being and great equality in health matters throughout the Community” (EU Health Strategy 2003-2008, 3)

The post-2003 texts focus more on the inequalities within the EU member states. The 2008-2013 EU program represents a very open and enabling stance towards inequalities and aims at addressing the “differences in health outcomes, differences in access to treatment and care, and differences between different groups within countries, such as between rich and poor, or between male and female”. Thus, we may see that his document seeks to empower those who experience inequalities within the healthcare system. The latest 2014-2020 document is more concerned with the inequalities of life expectancy and that “these health inequalities represent not only a waste of human potential, but also a huge potential economic loss”. In order to regain balance from these losses, the strategy suggests to implement a multisectoral approach and “focus on achieving greater gains in less advantaged groups than the average in order to close gaps”.

We may observe the theme of inequality as a process starting out from an inclusive approach in the earlier texts (i.e. spreading information to non-member states) to focusing in on EU member states and enhancing certain unequal sectors in order to not waste human potential.

8.2.3. Monitoring

Monitoring the progress of healthcare plays a critical role in all 4 documents. All the texts address it and regard it as a crucial tool for optimizing healthcare strategies for the years to come.

Pre-2003 texts regard monitoring as a tool of assessment for both community and national level healthcare initiatives, “ in order to increase the value and impact of the action programme, a continuous assessment of the measures undertaken should be carried out, with particular regard to their effectiveness and the achievement of objectives at both national and Community level" (1996-2000 EU Health Strategy, 3). The subsequent program of 2003-2008 suggest that the a "health monitoring system" should be established in order to successfully import information to healthcare programs for the following years "building upon specific determinants taken in the existing programmes, especially with respect to tobacco, nutrition and alcohol" (2003-2008 EU Health Strategy, 9). Furthermore, the Program also states that it imperative to compare and exchange results in order to improve information for the public and Member States.

Post-2003 strategies take the issue of monitoring a step forward. In the 2008-2013 document providing relevant and reliable healthcare information to people is seen as a right rather than an incentive. Therefore, the strategy states that monitoring healthcare data "is crucial for supporting decision-making at the health systems' strategic, control and operational levels, monitoring their implementation and evaluating their impact". Furthermore, the 2014-2020 document goes as far as to implement a new monitoring system in Europe by using the European Community Health Indicators (ECHI) and by assessing the cost-effectiveness of health systems, in order to "improve the knowledge and evidence on health expenditure and health outcomes in the achievement of structural reforms." (EU Health Strategy 2014-2020, 10)

9. Discussion

Through the use of frame analysis one is able to observe the different framings of patient empowerment through the scope of 24 years. All four documents had a different idea of the definition of patient empowerment; patient empowerment through health education, patient empowerment through health protection, patient empowerment through social understanding, and the practical (cost-efficient) understanding of patient empowerment.

Judging from the analysis of the four texts, the peak of patient empowerment was during the 2008-2013 cycle, when a huge portion of the healthcare strategy was preoccupied with the notion of patient empowerment. Moreover, the whole document was written in a manner of social understanding and advocacy for welfare procurements. Patient empowerment was seen as a core value within the medical sector, going as far as deeming it a right of citizens. This might have been an accompanying effect of the 2003 EPF establishment. However, this turned out to be a short-lived topic within official discourse. A sharp contrast may be observable in the 2014-2020 Health Strategy, titled Investing in Health. Here the patient empowerment is questioned and discussed in a skeptical manner. The Strategy declared cost-efficiency as its main purpose for the upcoming cycle. Unfortunately, patient empowerment is not seen as cost-efficient by the new program, only in the sense of patient taking care of their own conditions without weighing down hospital services and funds. The Strategy encourages the strategic overview and upgrade of all health care services in order to drive up efficiency.

The same tendencies may be studied in the 4 chosen themes as well, with the last two programs showing the largest contrast, rather than the pre-2003 and the post-2003 results. Albeit, there were two themes that stood out from the thematic analysis due to their homogeneous understandings; firstly, inequality was a theme that was saliently present in all four documents, addressing the issues of the differing levels of quality amongst member states. The second interesting theme was monitoring which was understood as a necessity in all of 4 documents, in order to further medical development in the years to come.

All in all, I will conclude that patient empowerment has not become a more powerful term over the years within the institutional rhetoric. Although, the concept itself is now outright addressed, it has apparently lost in value. If these documents are reflexive towards the European Union, one may infer that the topic of patient-centered care is not a priority to current leadership, as it was in the 2008-2013 cycle. It has become replaced with the substantiality of cost-efficiency in health care and is now seen as a high-cost investment of doctors' time and the government's money.

As aforementioned, the European Union is overwhelmed with hard pressing issues related to health care. However, difficult discussing points on patient empowerment are not only due to financial setbacks, but also due to the presence of huge gaps between health care systems. For example, many EU countries are suffering a brain-drain, i.e. the process of 'home educated' medical professionals leaving the country because of insufficient pay and medical environments and instead utilizing their training abroad; later, this process ends in an over-supply of medical care-givers. Examples of countries that had gone through extensive brain-drains are Hungary, Romania, Russia, etc., meanwhile countries that are now experiencing an over-supply of professionals are the UK, Switzerland and Germany. The brain-drain process is one of many factors that fed the widening economic gap between most Western and Eastern European Union countries. Due to the fact that these countries do not have uniform health care systems when observing training, regulations or quality, it is hard to enforce the same set of rules or patient empowerment rhetoric on them. Although, researchers such as O'Connor et al. recommend to set a standard for informed patient choice, thus ensuring a measurability of patient empowerment.

Probably one of the most significant contributing factors to the descending popularity of patient empowerment (within EU discourse) was the 2008 financial crisis. EU health care took one of the biggest hits during the consolidation period and still has not seen the end of its decreasing budgets. Because of the lack of unitary administration and legal groundwork concerning EU health care, health is one of the easiest targets for such budget shrinkage. Consequently, one may observe an overpowering presence of cost-beneficent policy-making, as well as a neo-liberal framing of patient empowerment; reductions of government spending, increasing privatization of government owned health care, fiscal austerity, deregulation, etc.

10. Conclusion

Patient empowerment has come a long way to become the concept that it is today. It aims to give patients the opportunity to take on an active role in the management of their own health. Originally, this movement was limited to specific patient communities, such as patients with chronic and rare diseases. These were patients that frequently had to return to institutional medicine in order to receive regular treatment. Through the expansion and development of human rights from the 1940s onwards, particularly after the end of the Cold War and the establishment of the United Nations, patient empowerement began to gain traction and expand. The emancipation movement in the 1960s was an additional push factor in the creation of the concept of empowerment. Subsequent to the 1980s HIV/AIDS epidemic, health communities began to assemble and support each other. However, a process of turning away from institutionalized medicine had begun. Health care started to lose touch with patients, become overly bureaucratic, overly complex, and overly expensive. In addition, medicine and biotechnology went through an incredibly fast paced transformation over the decades, to the sometimes impairment of the patient. A certain dehumanization of health care has become apparent; patients have become consumers, meanwhile health care has become business.

Through a qualitative research the thesis was able to shed light on the development of EU institutional discourse within the topic of patient empowerment. Patient-centered care has become a pronounced part of medical discourse. With the popularization of online patient communities and civil organizations such as the Quantified Self Movement, there has been a trend for patients to take their health back into their own hands. People have grown tired of their vulnerable positions in the clinical world. Patients have started to turn away from physicians and have begun to manage their own health conditions, through sites such as Patients Like Me or through technological gadgets such as the Pebble watch. Institutions are under pressure to react to the changes in patients' attitudes. Thus, they have started the process of creating forums and organizations that monitor and support the development of patient empowerment.

The research analyzed the institutional reaction of the European Union to the alterations in patient care. In 2003 the EU established the European Patients Forum which brought about a discursive shift in official EU rhetoric. Thus, the aim of the research was to find these changes in the discursive shift and determine whether the topic of patient empowerment has become more prominent over the past decade. The assumption of the research was that patient empowerment will be an increasingly recurring topic in the official EU rhetoric due to the EU engaging in the discourse of patient centered care through the creation of organizations, such as the EPF in 2003.

In order to determine the discursive shift that took place in official EU documents, in the topic of patient empowerment, the research analyzed four EU Commission Health Care Strategies, within a 24 year time-span. The findings of the research ranged from a strong pro-patient empowerment voice may be observed in the 2008-2013 EU healthcare strategy till the almost non-existent in the subsequent strategy of 2014-2020. Moreover, the 2014-2020 EU Commission Strategy views patient-empowerment as a rather skeptical form of patient communication and only urges its use if it provides means of cost-efficiency. Subsequently, many politicians have decided not to back the concept of patient empowerment, exactly because it is perceived to as a timely, costly and to some, unnecessary procedure. One of the main concerns is the high interaction price of elongated doctor-patient communication if the patient empowerment movement's popular health care model is to be followed, the Shared-Decision Making Model (SDM). However, studies have shown that when patients are actively encouraged to participate in their medical treatments and therapies they, themselves learn new means of monitoring and are able to communicate symptoms better to their clinicians. Thus, the consultation time is not spent with the doctor prescribing some sort of medicine on a trial and error basis, or by trying to deduce what the patients’ problem may be. Instead, consultations will become fruitful interactions between two experts; patient as the expert of her body, the doctor as expert of her profession.

The EU has many hardships to overcome when facing questions of health care. Across the EU, austerity measures were enforced in order to overcome public debt and fiscal deficit. Because of these cut-backs one of the first areas officials opted to take away money from was the promotion of patient empowerment and the promotion of patient-centered care. Although there is a clear and ever-accumulating movement that strives for shared decision making and better communication between patient and caregiver, patient empowerment was seen as a liability. This did not affect EU countries in a corresponding manner on account of that many EU countries are already top players in the patient empowerment game, such as the Netherlands, Norway or Switzerland. Yet, other countries, especially in the former Eastern bloc, patient empowerment is a much needed development in health care. This has become particularly apparent in the wake of the recent brain-drain crises as well as the overall quality slip of the health care system. Results have shown that patients who are taught to engage in shared decision making with their physicians show better health status results, an affinity to discover and learn more about their illness as well as a smaller chance of medical misdiagnosis.

In conclusion, patient empowerment provides the remedy to bridge the gaping crevice between institutional medicine and patients. The power of empowerment through information and understanding will once again humanize health care and fulfill its original purpose to ensure physical and psychological well-being of its citizens.

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