Introduction

The practice of medicine is one of the human activities that have undergone significant changes in the last 50 years. During this period, we have witnessed the transition from a basically paternalistic model, in which the patient was no more than the object of the application of medical science, to a new framework based on the idea of informed consent. In this new
paradigm, the patient—now empowered—is configured as the centre of medical care; it is the patient who makes the final decision on whether to receive a treatment on the basis of adequate information. Traditionally, this fundamental requirement—the acquisition of adequate information—was covered mainly through the construction of a doctor–patient relationship in which the latter relied on the information provided by the former and then decided on the option that best suited his or her preferences among those proposed by the doctor. This established a relationship between the doctor and patient based on trust and mutual cooperation that, typically, was based on the recognition of the health professional's better knowledge of medical science.

This framing of the relationship was subject to some criticism however. Indeed, authors such as Kreindler (2015) have pointed out that “The seemingly benign concept of patient-centred care can easily become a weapon on an intergroup battlefield. Understanding this dimension may help organizations resolve the intergroup tensions that prevent collective achievement of a patient-centred system” (p. 44). In the last few years, however, the patient-centred care model has changed dramatically due to the emergence of technologies that have substantially altered issues such as access to information, the volume of available data or the relevance of sources. This not only provides some advantages to both patients and healthcare professionals but also creates strong dysfunctions (Meghachandra and Devi 2014).

For patients, access to information that in previous times was not available can adequately complement the knowledge transmitted by healthcare professionals who, all too often, do not have enough time to explore in depth the pathologies of each patient. It must be emphasised that patients have, in theory, all the time at their disposal to focus on a single pathology, while practitioners have to contemplate a range that encompasses thousands of diseases. This makes it sometimes true that a patient knows more than a doctor about a particular pathology. This circumstance rather defies one of the main hypotheses of medical practice and is not always well accepted by the professional who has to provide healthcare.

This is not, however, the most pressing problem that has arisen in recent times. For every patient who manages to have a good understanding of his or her pathology, there are many more who end up being guided
by imprecise—if not clearly mistaken or misleading—information (Bynum 2008). Indeed, one of the problems we are currently facing is no longer a lack of information, but rather an excess of it. Furthermore, the difficulty of contrasting the available sources creates great anxiety in patients who often end up demanding treatments from a doctor that have no scientific validity whatsoever, proposing unrealistic diagnoses or assuming a risk perspective that is very far removed from reality (Nuffield Council on Bioethics 2014).

This situation often creates a scenario far removed from medical best practice. As Fiske et al. (2018) have written, “new types of mistrust within doctor–patient relationships have been documented and partly blamed on more—yet often unreliable—health information from sources outside of traditional clinical realms” (p. 39). The consequences of this end up being patients’ frequent recourse to self-medication, conflicts and even physical aggression to healthcare professionals, as well as a substantial increase in the stress to which health professionals are subjected (Bernburg et al. 2016). These circumstances create such a difficult scenario that sometimes a physician may end up agreeing to request unnecessary tests to avoid coming into conflict with the patient, which is conduct that not only borders on malpractice but also brings unnecessary economic cost to the public health system. This constitutes what has been called “wish-fulfilling medicine” (Buyx 2008)—that is to say, medicine adapted to what the patient demands, although its real usefulness is not clear. It is also quite clear that medicine à la carte does not really resolve these situations. We are currently witnessing a boom in direct-to-consumer tests, online diagnostics and telemedicine that often increase healthcare costs when the disconcerted patient forces their doctor to confirm or deny results via unnecessary new tests (Annes et al. 2010).

The primary aim of this chapter is to address a key question in this scenario: how might information availability be better managed so that the patient can relieve his or her anxiety and cooperate efficiently with healthcare professionals while avoiding all of the problems generated by an excess of information and health supply in the virtual space? While other chapters in this book also explore this issue using a variety of disciplinary approaches, here we deploy a socio-legal perspective and ask how the law might engage with this area. We therefore analyse the existing
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legal framework at the EU level and explore policy options proposed to enhance the current situation, including considerations of the role to be played by content providers, healthcare givers and providers, patient associations or newly created roles such as that of health information counsellors (HICs).

A Preliminary Distinction: Disinformation and Misinformation

One must begin the analysis of the role to be played by law in improving patients’ access to reliable information by recognising an undeniable premise: law cannot be the unique response to this main challenge. Freedom of expression is a fundamental human right, as we will show in depth in the following discussion. Therefore, legal restrictions to this right must be proportional, legitimate and proven necessary as the least restrictive means to pursue what they are aimed at. Under these conditions, the main question arises of when could we consider that such restrictions to freedom of expression would be both legitimate and necessary.

It is difficult to identify this precisely. Tracing a clear distinction between two different concepts—disinformation and misinformation—may help here. Disinformation includes “all forms of false, inaccurate, or misleading information designed, presented and promoted to intentionally cause public harm or for profit” (High Level Group on Fake News and Online Disinformation 2018). Misinformation, meanwhile, refers to “unintentionally false or inaccurate information” (Wardle and Derakhstan 2017). Misinformation is usually covered by the right to freedom of expression, and the law may find it difficult to deal with the issues this might create. Disinformation, however, is often considered an attack on the public interest that must be confronted by the law, even criminal law. In other words, we usually assume that it is legitimate for the law to prohibit disinformation, because it violates fundamental legal rights, a situation that set limits to freedom of expression. We can therefore arrive at a preliminary conclusion: legal tools can be efficient in prosecuting
disinformation, while misinformation creates a challenge that is hard to address through the law.

There are circumstances that may make things more difficult. Unfortunately, in practice, it is not easy to distinguish whether something should be considered disinformation or misinformation. For instance, if a terrorist group plans to cause harm by creating fake news about a false pandemic, if someone disseminates inaccurate medical information to earn huge sums of money or if a clinic offers stem cell therapies that do not work at all, we might clearly consider these to be examples of disinformation. Obviously, these cases might be driven by different criminal purposes, but they would all share a common element: the intention to cause public harm or earn money by purposefully providing false, inaccurate or misleading information. There are, however, some other cases in which this distinction is not so clear. Homoeopathy and the information that some providers could bring about its real utility may be one example of this—and perhaps makes it easier to imagine how difficult it could be to distinguish disinformation and misinformation. We must therefore clarify in advance that, although we are dividing our analysis into two parts corresponding to the legal response to both types of conduct, in practice it might be very difficult to determine these boundaries.

**Fighting Disinformation with Legal Tools**

As mentioned, although misinformation constitutes a clearly censurable practice, it is difficult to fight from a legal point of view, because it stands very close to (if not directly in) the territory of freedom of speech. Indeed, the European legal framework is marked by the fundamental moral tension between freedom and responsibility. Article 11.1 of the Charter of the Fundamental Rights of the European Union, which, with the entry into force of the Lisbon Treaty in 2009, gained the same binding legal status as the European Union treaties, emphasises the importance of freedom of expression as follows: “Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public
authority and regardless of frontiers” (Charter of the Fundamental Rights of the European Union 2019). Similar is the sense of Article 10 of the European Convention on Human Rights (ECHR), which underpins the activity of the Council of Europe and binds its Member States. The first paragraph acknowledges the salience of freedom of expression, while the second points to the duties and responsibilities attached to its exercise.

It is of course true that responsibility may impose restrictions or penalties prescribed by law and necessary in a democratic society, which can be justified inter alia by the interest of public safety and the protection of health (Charter of the Fundamental Rights of the European Union 2019). However, the jurisprudence of the European Court of Justice (ECJ) has specified that these eventual limits of the freedom of speech must be interpreted “restrictively” and “reserved for the purposes of a “pressing social need” and with a “relevant and sufficient” justification” (Connolly/Commission (C 274/99) §41). Moreover, as the ECJ states, “the restrictions must be prescribed by legislative provisions which are worded with sufficient precision to enable interested parties to regulate their conduct, taking, if needed be, appropriate advice” (Connolly/Commission (C 274/99) §42). This legal framework clearly shows the underlying philosophical tension between freedom of expression and the right to be properly (and responsibly) informed, as well as showing how sensible and “soft” the legal instruments applied to such cases should be. Nevertheless, this evidence does not mean that laws can do nothing to reconcile freedom of speech with the defence of basic public goods, such as the right to adequate, evidence-based healthcare.

Indeed, in the EU and its Member States, there are a number of legal tools that have been approved in the last two years to fight disinformation, such as the Communication on Tackling Illegal Content Online, the Recommendation on Measures to Effectively Tackle Illegal Online Content or the Communication on a European Approach to Tackling Online Dissemination. To this must be added the proposed Regulation on the Prevention of the Dissemination of Terrorist Content Online.

At the national level, it might be worth highlighting some legal actions introduced in countries such as Germany. In October 2017 the Network Enforcement Act (NetzDG, Gesetz zur Verbesserung der Rechtsdurchsetzung in sozialen Netzwerken, also known as the “Facebook Act”) entered into
force; this act facilitates the imposition of a fine of 50 million euros on social media platforms that fail to remove content that is manifestly unlawful within 24 hours of receiving the complaint. For content that is offensive but in a less manifest manner, a seven-day assessment period is allowed, and failure to comply with this may also lead to a company being fined.

In France, a bill on disinformation was passed in 2018 that reinforced the principle of transparency by obliging social media platforms to disclose who sponsored particular content and for what amount of money. The companies failing to fulfil this obligation could face a fine of €75,000. However, only a week after the Parliament approved it, senators from the French Republican Party (LR) and the Centrist Union group appealed to the Constitutional court over the law, and the bill is still pending.

The Czech Republic created a special Centre Against Terrorism and Hybrid Threats at the Ministry of the Interior. The aim of the Centre is to monitor threats directly related to internal security, which also include disinformation campaigns also related to internal security. Based on its monitoring work, the Centre evaluates detected challenges, comes up with proposals for substantive and legislative solutions and implements them where possible (Centre Against Terrorism and Hybrid Threats 2019). It also disseminates what it regards as accurate information and counters the false statements by, for example, publicising available facts and debunking fake stories. As the Ministry emphasises, the Centre will not force the “truth” on anyone, or censor media content; neither will it remove content from the Internet or other (printed) media.

It appears, therefore, that there are several legal tools, both at the EU and the Member State level, aimed at fighting disinformation. Most of them, however, tackle particularly worrying types of disinformation, such as terrorist attacks or disinformation (or influence) operations—that is, commercially or politically motivated manipulation strategies, a variant of intentional disinformation at a much greater scale (Policy Department for Economic, Scientific and Quality of Life Policies 2018, p. 5).

However, not all varieties of disinformation should lead to a block on the spread of information via hard law initiatives, because this would dramatically impoverish our democracy and society. Indeed, the regulator would then be promoting practices that violate freedom of expression
and other fundamental rights, leading to censorship, online surveillance “and other misguided responses that can backfire substantially, and that can be used by purveyors of disinformation in an ‘us vs. them’ narrative that can de-legitimize responses against disinformation and be counter-productive in the short and long run” (High Level Group on Fake News and Online Disinformation 2018).

On the other hand, it is necessary to keep in mind that offences related to disinformation often include in their wording a reference to actions directed “to intentionally cause public harm or for profit”. Intention therefore plays a key role in determining whether the diffusion of false information about health can be considered disinformation. The problem is that, too often, the intention to provide inaccurate information to harm or to profit is not clear. Providers are usually well aware of the legal framework and often avoid conveying an obvious falsehood. Rather, they opt for a certain ambiguity that induces error but does not inevitably cause it. For instance, laboratories sometimes promote their genetic tests by providing patients with information that is only partially accurate but could hardly be defined as deceitful. In such cases, it is quite difficult to prove that disinformation as such exists, so sanctions would not be applicable. As a result, penal or administrative law based on fines or penalties might be an inadequate tool to fight disinformation of this type.

Alternative tools might work equally well without affecting freedom of speech. In this respect, the Policy Department for Economic, Scientific and Quality of Life Policies of the European Parliament distinguished three main policy types advisable for this intricate task: (1) the promotion of responsible behaviours in disseminating the information among providers of information, (2) the enactment of a proactive media policy aimed at promoting pluralism and exposure of diverse content among its recipients and (3) as the Department formulates it, improving media literacy and supporting user behaviours that “can take the form of ‘hyper-nudges’, i.e. ways to focus the attention of end users on a diverse set of contents, and to discourage them from sharing non-verified content” (Policy Department for Economic, Scientific and Quality of Life Policies 2018, p. 21).

The most decisive legal action undertaken by the European Commission that can be subsumed under the first of the above categories—“promotion
of responsible behaviour among information providers”—was issuing the EU Code of Practice on Disinformation. This unprecedented document was signed by the most relevant private stakeholders in the field including Facebook, Google, Twitter and Mozilla, as well as professional associations representing both Internet platforms and the advertising industry. The Code applies to cases of disinformation—as opposed to misinformation—defined as a “veritably false or misleading information”. To be counted as disinformation, a piece of information must cumulatively fulfil the conditions of (1) being “created, presented and disseminated for economic gain or to intentionally deceive the public” and (2) being a possible cause of “public harm, intended as threats to democratic political and policymaking processes as well as public goods such as the protection of EU citizens’ health, the environment or security” (EU Code of Practice on Disinformation 2018).

The sting in the Code is therefore aimed at political and issue-based advertising on social media. Obviously, the second category applies to healthcare issues in a more direct way, but this does not mean that the category of political advertisement remains unrelated. There are many potential (or real) situations when ostensibly false or misleading information could be used for political aims, such as to spread political and social anxiety (Broniatowski et al. 2018). An example of such a case would be the social media rumours circulating during the outbreak of Ebola in 2014, which, as Chou et al. (2018) have argued, triggered hostility towards healthcare workers and hindered control of the epidemic. The most repressive of the provisions of the Code is the commitment of its relevant signatories not to accept remuneration from, or otherwise promote, accounts and websites that consistently misrepresent information about themselves (EU Code of Practice on Disinformation 2018, Commitment II A.).

There are also many other, softer, means designed to counter the spread of disinformation. Most important, in the context of healthcare, are those directed at empowering consumers and the research community. The signatories have committed to invest in products, technologies and programmes that may both prioritise relevant, authentic and authoritative information and help individuals make more informed decisions about the trustworthiness of the provided information (EU Code of Practice on
Disinformation 2018, Commitment II D.). They have also agreed to cooperate with academics and civil society organisations (including an independent network of fact-checkers) in their good faith efforts to track disinformation and understand its impact (EU Code of Practice on Disinformation 2018, Commitment II E.). The discussed commitments are, undoubtedly, a very soft and low-interference form of legal intervention into the practice of diffusion of information on social media; however, as the Code envisages various means designed to monitor and enhance the effectiveness of its implementation—such as signatories’ annual self-assessment duties and regular follow-up meetings—they may bring positive results. It may thus be hoped, that, in the long term, the actions and commitments undertaken in the Code may also increase the transparency of information provided in the area of healthcare and improve people’s media-related health literacy.

Another important legal tool for facing the challenges posed by the tension between the right to free expression and responsibility, underlying the EU legal framework, is the latest opinion of the European Committee of the Regions on tackling online disinformation, which strongly emphasises the salience of the latter—obligatory—aspect of freedom. As the Committee rightly points out (Opinion of the European Committee of Regions 2019), the hallmark of social media is an inherent lack of responsibility caused by the fact that, unlike “traditional” media—which are governed by professionals (journalists, editors and administrators) who must regularly account for the content they create—information disseminated on social media is created by non-professionals and often highly anonymised (with its authors being not only unknown but difficult to identify).

To counterbalance this inherent lack of accountability on social media platforms, the Committee formulates four governmental strategies to fight disinformation, including the following: (1) increasing transparency, (2) promoting the diversity of information sources, (3) developing a system for assessing the reliability of information sources and (4) introducing civic education programmes. The latter dimension to improve users’ media-related literacy is regarded by the Committee as the best long-term solution and investment by regional and local government is strongly advised.
This is also potentially the most productive strategy in the domain of healthcare, where both providers and patients could profit from improved media-related skills. This claim may be strengthened by the annual Edelman Trust Report, which in 2018 for the first time investigated the (declining) levels of trust in healthcare and formulated the following conclusion (among many others): to maintain patients’ trust in today’s post-truth era, healthcare should be “their own publishers” (Edelman 2018). As the report states, information provided by health companies is usually viewed as credible, whereas, on the global level, only 53% of people trust health news reported by the media. Therefore, health companies should “leverage their own channels to share their stories” rather than leave this task to the media. Leveraging such channels should mean not only creating attractive and commercially productive Internet profiles but also providing the public with reliable, evidence-based medical information. The potential improvement in social media usage from healthcare professionals must go together with the general effort to increase health literacy among individual patients whose unskilled consultation with “Doctor Google” (Bryan 2019) may bring many detrimental effects to their personal, as well as to the public, health. However, there is one caveat to his approach. The whole Eurobarometer survey series reflect how peoples’ opinions are not based on knowledge alone, but rely on values and preferences of different types. There is more than dis- or misinformation that will guide the reading of health-related information, and thus literacy will be an answer for some, but may be not as crucial as one might think (Eurobarometer: Survey Series—GESIS).

**Misinformation: An Extremely Challenging Scenario for the Law**

The above-described legal means are aimed at fighting disinformation. Misinformation, as a much more subtle and nuanced phenomenon, is, in the light of the fundamental place of freedom of expression in European democracies, much more difficult to tackle from a legal perspective. As misinformation is spread without any intention to deceive the public, the
application of repressive legal means would be misplaced in most of cases. However, the above-discussed documents already provide a wide and interesting repertoire of proactive legal strategies that could be successfully applied in the domain of healthcare. These are (1) increasing transparency, (2) proactive media policy on the side of healthcare providers and (3) introducing civic education programmes. To these might be added some alternative but potentially useful tools in the context of healthcare, such as the creation of a new type of professionals: the so-called health information counsellors.

**Increasing Transparency**

The first of these policies is one of the most popular strategies (European Commission 2016) being introduced to re-establish declining trust (Edelman 2017) in many European democracies. It is important and potentially effective in the political realm, which is characterised by an inherent conflict of interest often leading to many mis-statements and malpractices that, as such, should be kept under public scrutiny. In an apparently golden era of democracy (when the Cold War has already been “won”, and Eastern Europe liberated for the democratic model, as Francis Fukuyama declared in his “end of history” thesis (Fukuyama 1992)), Piotr Sztompka (2000) has formulated a famous, and often quoted (Warren 2018), paradox of democracy: trust in democracy is based on the mechanisms of institutionalised mistrust, such as judicial review, civil disobedience and checks and balances, provided that—and this is the second paradox—they are not used too eagerly.

The politics of transparency is one of the mechanisms of “institutionalised mistrust” that is most open to the public and particularly apt for our contemporary “post-truth” (Flood 2016) times, where the overflow of information has diminished its credibility and transparency. It must be remembered, however, that Sztompka’s paradox has a second side: these mechanisms cannot be used over-zealously and too often, because they can yield an adverse effect. This adverse effect consists of “crowding out” (Bohnet et al. 2001) genuine, interpersonal or institutional, trust by overprotective or overly coercive legal mechanisms.
The necessary limits of the culture of transparency are wisely indicated by Ivan Krastev (2013) in the context of contemporary democracy, as well as in the already classic work by Onora O’Neill on autonomy and trust in bioethics. As O’Neill insightfully stated: “Members of the public can access information about the remit, membership, current work and reports of public bodies. Major companies, universities and charities provide increasing amounts of information on their websites (...). Yet despite all these changes, and all these measures of improving trustworthiness, public trust still falters” (O’Neill 2002).

It is beyond doubt that in an era of increasing malformation, some transparency measures should also be taken in healthcare. This could take the form of a network of medical fact-checkers designed to counter specific medical kinds of misinformation, such as debunking and correcting paramedical “revelations” on alternative, miracle therapies, unproven wellness supplements advertised by celebrities or ubiquitous irrational and anti-vaccination arguments that are so widely spread on social media. Because healthcare is one of the most significant institutions of public trust, it is important to implement policies of transparency with due, healthcare-specific caution. Rather than multiplying the mechanisms of institutionalised distrust, more effort should be invested in the proactive and educative media policies described below.

**Enacting Responsible and Proactive Policy on Social Media**

The second recommended strategy would be to enact a responsible and proactive policy on social media. In the case of healthcare, this could mean creating partnerships among healthcare entities, trusted social media influencers, marketing firms and technology companies. The aim of such a partnership would be to establish diverse online channels disseminating accurate, evidence-based medical information in an accessible and Internet-friendly way.

Another form of this strategy would be to partner with advertisement agencies to create an interactive Internet page (or social platform profile) for a given healthcare entity (as the Edelman report advises: be your own
publisher) that would disseminate evidence-based medical data in an interactive way, such as by answering questions posed online by patients, preventing their reliance on their own unprofessional and often distorted interpretation of information they find for themselves on the Internet.

A third implementation of this proactive social media strategy would be contacting social media influencers and asking them to share trustworthy medical content with their followers, which, as Collier (2018) has argued, has already proven to be effective. It is worth mentioning that this type of proactive media policy was explicitly recommended by the Council of the European Union to strengthen cooperation against vaccine-preventable diseases (recommendation 6), which obliged Member States to “increase communication activities and awareness-raising on the benefits of vaccination by: (a) presenting scientific evidence in a form understandable to laypersons, using different context-based strategies, to counter the spread of misinformation, including, for example, through digital tools and partnerships with civil society and other relevant stakeholders; (b) engaging with and offering training for relevant actors, such as healthcare workers, education stakeholders, social partners and the media as multipliers, to fight complacency and increase trust in immunisation” (Council of European Union recommendation of 7 December 2018).

The Education of the Civil Society

The third strategy, strongly emphasised by the opinion of the Committee of Regions described above, is civil education, which, indeed, is the best way to counter both disinformation and misinformation in the long term. A critical and selective approach towards information found on social media is the key to responsible interpretation. Possible educational programmes should not only be directed at patients but also at healthcare workers. Doctors, nurses and medical assistants should be trained to cope with patients’ Internet-based convictions in an open, professional and respectful manner (Bella et al. 2008.)

This, however, would require governmental initiatives such as introducing technology-oriented courses within medical studies and special
training for current active medical professionals. Some interesting tools have already been developed for this purpose; in Canada, for instance, the CanMEDS framework identifies and describes the abilities physicians require to effectively meet the healthcare needs of the people they serve. These abilities are grouped thematically under seven roles, and a competent physician seamlessly integrates competencies from all six of these: communicator, collaborator, leader, health advocate, scholar and professional. If the physician has mastered these abilities, he or she becomes a medical expert who can provide high-quality, safe, patient-centred care, drawing upon an evolving body of knowledge, clinical skills and professional values (Royal College of Physicians and Surgeons of Canada). Of these, perhaps the most helpful in allowing physicians to deal with information technology are those of physician as communicator, physician as health advocate and physician as a scholar. As communicators, physicians form relationships with patients and their families that facilitate the gathering and sharing of essential information for effective healthcare informed by evidence and guidelines. Physicians explore the patient's perspective, including fears, ideas about the illness, feelings about the impact of the illness and expectations for healthcare and healthcare professionals. The physician integrates this knowledge with an understanding of the patient's context, including socio-economic status, medical history, family history, stage of life, living situation, work or school setting and other relevant psychological and social issues.

As health advocates, physicians contribute their expertise and influence as they work with communities or patient populations to improve health. In this role, physicians support patients in navigating the healthcare system and advocating for patient access to appropriate resources in a timely manner, as well as gathering information about issues and working with patients and their families to develop an understanding of the needs and potential mechanisms to address these needs. As scholars, physicians are expected to demonstrate a lifelong commitment to excellence in practice through continuous learning and by teaching others, evaluating evidence and contributing to scholarship, and they are able to identify pertinent evidence, evaluate it using specific criteria and apply it in their practice and scholarly activities.
Similar considerations should be applicable to nurses, who also play an essential role in healthcare delivery. Core nursing competencies can be described as the ability to understand people and situations. This means that nurses must have the ability to apply knowledge, understand patients’ needs and, based on this, develop an adequate clinical judgement. Moreover, they need to have the ability to build supportive interpersonal relationships through communication. Nursing competencies consist of the integration of knowledge, including professional judgement, skills, values and attitudes, which represent an intelligent practical skill set that integrates or combines different factors and issues in complex ways, specific to each circumstance encountered in clinical practice. To acquire nursing competency, nurses must possess the skills and personal traits necessary to perform their duties effectively while integrating multiple elements including the knowledge, techniques, attitude, thinking ability and values that are required in specific contexts (Fukada 2018).

It must therefore be concluded that, by looking at physician and nursing competencies, one finds significant input that could help in communicating and understanding the complexities of big data and health information technologies in today's healthcare delivery system. Should we change healthcare curricula so healthcare providers can also have competencies in health information provision? By looking at the CanMEDS framework and nursing competencies, this would seem to be a reasonable solution.

An alternative tool to improve the education and support of civil society is the inclusion of patients in the processes. Patient associations are efficient agents for improving the performance of the system. They have traditionally provided a supporting role for patients, and their activities are constantly developing and evolving. Historically, the sharing of patients’ experiences of their own disease was the key reason for establishing patient associations. Many patient associations still provide face-to-face opportunities to meet and discuss pathologies. However, much interaction now takes place online, through blogs, Internet forums and websites. Patient associations help people to understand their condition(s), and many still provide comprehensive and clear information on paper, but this is being supplemented with websites, videos and social media.
More recently, patient groups have become involved in scientific and therapeutic activism. The concept of the “expert patient” or the “expert of experience” has developed (as is discussed in Chap. 6). The expert patient provides input into research and healthcare using his or her unique expertise as someone with first-hand experience of a disease. Many patient associations have designed processes and methodologies to ensure that their members are fully prepared to get involved in areas such as research and clinical trials and ensure that patients are available to participate wherever needed (European Lung White Book 2019). It therefore seems that patient associations have been able to keep up with the new technological developments and contribute effectively in improving the education and training of patients and civil society in general (Werder 2015).

**Alternative Tools**

Finally, it is worth mentioning that some authors consider that physicians and nurses are not adequately educated to navigate the complexities that have emerged because of the increasing range and quantity of digital information available for healthcare purposes. This can put significant strain on the healthcare giver–patient relationship. There have been numerous discussions and calls for better training of healthcare providers in big data, assessing treatment options using online resources and comparing information from different online sources. A new profession that would help both healthcare providers and patients has been proposed: the health information counsellor (HIC) (Fiske et al. 2018). The basis of this suggestion is clear: with the advent of big data, the healthcare provider–patient relationship is undergoing a change that appears to be detrimental to the main issue at hand when it comes to this relationship—trust.

This is a familiar scenario. At the end of the twentieth century, with the revolution in genetic and genomic sciences and the introduction of genetic testing, a new strain was placed on the physician–patient relationship. Physicians needed to be able to navigate the complexities of explaining genetic test results to their patients. Additional training was introduced and a new profession founded: genetic counsellors (Skirton et al. 2015).
Now, with the advent of big data, online healthcare services and electronic healthcare records, there is again a need to somehow “help” physicians and (especially) patients better understand and navigate the complexities of modern healthcare delivery through the invention of the health information counsellor (HIC).

What would be the role of the HIC? According to the literature, their role should be broader than that of genetic counsellors. HICs should be prepared to help patients evaluate the reliability of commercially available tests (including genetic tests), assess treatment options and compare information from online sources with physician recommendations. Does this mean that the genetic counsellors should cease to exist as a profession and reinvent themselves as HICs? This remains to be seen (Fiske et al. 2018). There are certainly many ethical issues arising from the new approaches to healthcare delivery that may have an impact on the everyday physician–patient relationship. Can HICs also be a sort of ethical consultant? This is still not clear from the discussions in the literature, although ethical competencies applied in big data settings are necessary for HICs.

When discussing the skills and competencies that HICs should possess, as well as how their training should look, it has been suggested that HIC training should take place in interdisciplinary programmes affiliated with medical schools. The fields of epidemiology, biomedical statistics, genetics/genomics, computer science, science education, social medicine, ethics and health policy should be covered. These programmes should be part of postgraduate training. Persons with degrees in health or natural sciences—including physicians—would be eligible to apply.

It seems that the notion of trust and mutual partnership in the physician–patient relationship may be called into question by the role of HICS, whose purpose is to help both parties muddle through the complexities of digital data in healthcare delivery. Is there really a need for HICs or should we change medical school curricula so that healthcare providers (i.e. physicians and nurses) can also serve the role of HIC? The answer to this question remains to be seen.
Conclusion

Social media and new technologies—including discussion boards, social network sites, blogs and videos—may be excellent tools to guarantee adequate patient-focused healthcare or contribute to improving the healthcare system by providing alternative sources of training and surveillance. However, their use also raises concern about misinformation and disinformation that might cause serious harm to the patient–doctor communication and relationship. Such use might also induce the patient to make wrong decisions on the basis of non-scientific knowledge or even provoke a threat to public health if a patient suffering from a contagious disease refuses treatment due to misguided advice, as happened in some contexts in regard to the COVID-19 virus in 2020. It is therefore perfectly understandable that all collectives involved are increasingly concerned about the need to regulate these activities in a way to serve the interests of all involved.

This chapter contributes towards the book’s overall multidisciplinary exploration of the digital health landscape, inasmuch as here this landscape is in part being shaped by the examples of the various new legal interventions in the management of information discussed above. These should help patients, carers and others to navigate this landscape in a more reassured way. In order to fulfil this task, we analysed these issues from the perspective of EU law and policy recommendations on management of information. We provided an updated commentary on the EU legal framework applicable to online activities in the digital environment including the Internet and social networks, in the healthcare context. This comprises topics such as the regulation and policy tools developed by the EU concerning social networking communities and data-sharing platforms that include the sharing of sensitive information, such as health data, as well as the role played by patient organisations in improving available information. In doing so, we have highlighted the main issues and gaps that currently exist and analysed the measures proposed by EU institutions to improve the situation. We discussed a very soft and low-interference form of legal intervention into the practice of diffusion of information on social media, as well as various means designed to
monitor and enhance the effectiveness of its implementation. Hopefully, this will serve to guarantee an optimal development of these new technologies, while preserving healthcare workers’ interests, patients’ health and basic public goods.

Acknowledgements Iñigo de Miguel Beriain’s work was supported by the Government of the Basque Country, Grant IT-1066-16, and the EU Commission, H2020 SWAFS Programme, PANELFIT Project, research grant number 788039.

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