

EU Health Place - Social Network for Health

Balancing Human Rights Online Through “Action” Regulation

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If we are to effectively modulate the benefits and harms from social networks and misinformation, there is an inherent value in the “audacious” idea of creating a publicly owned social network at the EU level. A balance between freedom of speech and dangers of misinformation has to be found. I would call this “action” regulation by means of digital infrastructural action. The European Health Data Space Regulation would benefit from social thinking. The EU needs to act now.



Key Points

- There is currently an overabundance of information, available both online and offline, much of which is health related mis- and disinformation. The WHO have coined this phenomenon an “infodemic” with the obvious “pandemic-like” connection implied.
- Human rights may be in conflict: the right to Freedom of speech, “anonymity and hiding” and the Right to health (protection), misinformation and infodemics.
- The “regulation in action” concept is presented through a realistic proposition: the creation of a social network for health, the EU health place, within the European Health Data Space (EHDS).
- The EU health place would provide a safe space for citizens and patients to securely talk about health wellness and their concerns, whilst being protected from misinformation and fake news by public health authorities and patient associations who participate equally in moderating activities.



Introduction

European Commission President Ursula van der Leiden has alluded to the need to have an EU action on social networks, misinformation, disinformation or “fake news”, and its’ risks to public health (EC Twitter post 2021). Yet most of this activity transpires within US-based, privately-owned social networks where Europeans (among others) connect and express their freedom of speech. In utilising these social networks, they also submit voluntarily to US companies’ terms-of-use and to speech moderation (human or via artificial intelligence or other algorithms) and expose themselves to significant and raising levels of mis- and disinformation. In health, the WHO have coined this phenomenon an “infodemic” with the obvious “pandemic-like” connection implied (WHO 2021). The term infodemic can be addressed in regards to literacy, however, some experts caution that it might be better to more clearly link infodemic with communication.

One way to deal with such issues is looking at it from a “regulation in action” perspective. This means, the State, or in this case the Union, endures the cost of creating a public space with “democratically enacted rules” as an effective guardian of human rights, particularly when these are at conflict and dynamic balances have to be found.

In health, there is an inherent value in the “audacious” idea of creating a publicly owned social network at the EU level, under the umbrella of the European Health Data Space, an action currently being discussed (Figure 1). This could provide a safe space for citizens and patients to securely talk about health wellness and their concerns, while remaining protected from misinformation and fake news by public health authorities and patient associations who participate equally in moderating activities.

Human Rights at Stake

Right to Freedom of Speech, “Anonymity and Hiding”

The right to freedom of speech is generally present in most liberal democracies. While in open public spaces, such as streets, parks, or a beach, in its oral form this is generally not legally problematic. Personal insult or directly damaging speech are generally quite well covered by civil law in most jurisdictions. The plaintiff can exert a right of protection from defamatory speech, highly abusive, aggressive, or threatening speech. The fact that the speech does not “sustain in time” significantly reduces damage, and since spread is naturally limited, the damage potentially caused due to a large number of people being made aware of this information (or mis-information) is also limited. The anonymity of the emitter is very difficult (albeit possible), which means the accountability and, hence, liability is very high.

In classic printed forms: papers, magazines, books etc, the reach enlarges, the spread, although faster, is somehow limited to copies available, and the anonymity is possible (pseudonyms) as well as traceability, although quite

The European health data space will:

- 1) promote safe exchange of patients’ data (including when they travel abroad) and citizens’ control over their health data;
- 2) support research on treatments, medicines, medical devices and outcomes;
- 3) encourage the access to and use of health data for research, policy-making and regulation, with a trusted governance framework and upholding data-protection rules
- 4) support digital health services;
- 5) clarify the safety and liability of artificial intelligence in health.

Source: European Commission (2021) Digital health data and services – the European health data space (europa.eu)

Figure 1. European Health Data Space

dependent on editors and their rules. Hence, direct responsibility for speech could be asked from author or from the editor in case the author’s identity could not be found. This means there is generally someone to be called in to step in front of a judge or jury.

Finally, in online social networks, in platforms like Facebook®, Twitter® or YouTube®, for example, the level of impact and speed of dissemination of false information is very high and fast. Persistence over time is almost unavoidable, and control, in this case by private companies, is somehow dependent on existing terms of contract and on the arbitrary decisions of these companies to take down, block or somehow filter, mostly a posteriori content. Anonymity is possible (this is less so now than in the past, as registration processes are increasingly requiring mobile phones numbers, or “real” emails, which somehow ensures a link to personal data of a “real legal subject”). Traceability is difficult, although its possibilities are increasing due to the same trends in registration.

This means people can quite easily create fake news, disseminate false healthcare suggestions, counter-inform, for example against COVID-19 vaccination, thus creating misunderstandings in less informed, capable and literate or people who are likely to be more easily influenced. This can place the person, or, more widely, a population at risk of an adverse health outcome as a result of incorrect behaviours such as drug intake, delayed vaccination, delayed screening, etc. Thus, reducing their right to health protection.

At another level, one can analyse if the right to free speech is equal to the right to “anonymous” and “untraceable” speech. Such was obviously less relevant in the early days of free speech rights movements, but now, in digital platforms it gains relevance, since in few seconds, a “faceless” information piece can reach millions of other individuals.



Right to Health (Protection), Misinformation and Infodemics

“A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities. (...)”

*Treaty on the Functioning of the European Union (TFEU)
– TITLE XIV – Public Health Article 168 (n° 1)*

“(...) A high level of human health protection shall be ensured in the definition and implementation of all the Union’s policies and activities.”

*Charter of Fundamental Rights (CFR)
Article 35: Healthcare (Hooker 2019)*

This means that in the EU, a Human Right to health protection has been recognised. More so, the Union’s activities can bear relation to such right, hence, so do the actions of the European Commission. (Note that the CFT is at the same legal footing as any other article of the TFEU by means of TEU Article 6: “The Union recognises the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union of 7 December 2000, as adapted at Strasbourg, on 12 December 2007, which shall have the same legal value as the Treaties”).

This right means that humans, in the EU, are entitled to the protection of their health, not just through their national constitutions, but even by European Law. Not being exposed

to false, contradicting or misleading information that could lead to behaviour that increases the risk of damage to health is part of this right. As way of an example, it is this legal basis that allows the prohibition of advertising tobacco products in many countries. One could say that citizens would have the responsibility for acting upon such advertising and hence, no grounds for prohibition would exist as there would be no direct link between damage to health and the “free speech” of tobacco companies, and yet this prohibition is enforced in most media. Now if a tobacco fan, who happened to live until 75 years old, decided to post his experiences on a social network and suggest that his “secret to longevity” was smoking and that public health authorities are wrong, would this be “fake news”, or misinformation? Would there be grounds to ask him/her to remove his post or simply automatically or manually remove this? Possibly the answer is no. What if one out of three members of a social network do the same? Would this not be likely to influence others into smoking and in that case, could there be grounds for action to ensure “a high level of human health protection” by means of digital moderation? The size and scope of this paper do not allow me to dissect these questions, just to say that they stand at equal footing to contemporary legal debates on freedom of speech moderation, and the inherent risks for democracy. Inversely, not moderating misleading information and highly influential information can equally pose a risk to the health of the inhabitants of such democracy.



Balancing Rights and Conceptualising Online Public Space

While doubts will remain, as we balance the two rights put forward, the fact that most of this “public speech” is happening on private media suggests two possible routes of action. Both relevant for the Union:

One would be to conceptualise that, although private entities own social networks, and most of them are non-EU companies; they are in effect bound to follow EU law, applicable to EU citizens, data and expressed opinions, posts, video uploads etc. In this case, a directly applicable Regulation, such as the GDPR would need to be enacted, with severe restrictions to the element of informed consent, and possibly infringing on “the general right to liberty.”

The other would be to conceptualise that any space where a significant number of people meet to exchange their views, share and do things “together”, although virtual in nature and digitally supported, even if by a private company, is de facto a public space. This means public space “rules” could be enacted in similar ways, making no distinctions.

If one accepts the second view, an additional question arises. Should not public health authorities participate in such spaces? Not just as “citizens” as they are now considered by most social network companies – with the same terms and rules, but as “true” public health authorities, with the prerogatives that derive from that. For example, this would provide the capacity to limit an activity economically or just its’ advisement, solemnly based on health protection grounds. This equally would mean they would need to participate in any “due process” of speech moderation online. It is quite difficult to foresee that EU level or national level public authorities are likely to gain such prerogatives, particularly in US-based companies. Prerogatives, which seem to me, to be quasi-essential for effectively influencing speech moderation online.

An Orthodox Solution – “Action” Regulation

An alternative option, admittedly counterintuitive is for the EU to work up its digital sovereignty, by creating a “Public Space” about health wellness and healthcare. This would be a space for patients, citizens and their associations, to interact with each other as well as with public entities, trusted health information providers and health promotion agents. Such space can be part of the EHDS. Through public funding and public law rules, the role of public “democratic” authorities could be ensured; “due processes” for dealing with whatever needs to be defined as inadequate content, through a mechanism of “action” regulation would equally become possible.

In summary, under proposal is a public social network for patients/citizens and public health agents, where true identification (hence traceability) is possible as well as mechanisms of data altruism. Anonymous and non-anonymous sharing of health issues, peer support, interactions in general are both possible at a person-to-person level if solid (block-chained, or other cyber-secure) pseudo anonymisation mechanisms are made available.

Next Steps

The contributions on the European Health Data Space Regulation presently under consultation benefit from social thinking. Sociologists, social psychologists and as well as other social science experts can be involved in thinking the European Health Data Space as a socio-technical project and not just as a digital health project. Such a narrow-minded approach may miss out on important factors such as motivation, engagement, and emotional distancing. Perhaps more importantly, regarding the infodemic problem, it may miss out on potential evolutionary and somewhat “revolutionary” solutions. One such solution is to brand this platform, as a “health place”; that is, a social networking place for all professionals, patients, citizens and health promotion authorities.

The EU does not need to be passive in this regard. It can act by including the concept of a “EU Health Place” within the set of digital services to be contained within the EHDS currently under discussion and conceptualisation. Instruments such as Coordination and Support Actions, or other EU funding instruments can be utilised to create the relevant community and concepts. Also some of these instruments are equally suited to fund the actual creation the “EU Health Place” to foster health multi-professionalism and patient literacy, empowerment and enlightenment.

Conclusion

It is proposed that a “publicly owned” social network be part of the EDHS as a mechanism to balance the right to freedom of speech and the right to health protection in the EU, from misinformation and infodemics.

What is the alternative? The status quo means allowing the flow of information to continue to occur in unregulated, unsafe and to a certain extent, unethical and unjust ways in privately-owned social networks, which are mostly regulated by non-EU law. It is clear that general regulatory approaches regarding the health domain are ineffective in curbing the current infodemic.

The EU should not remain passive with regards to health topics in non-EU social media. There is a global infodemic underway and as such, misinformation and fake news are a considerable threat to the health of EU citizens. As outlined succinctly in this paper, the time to act is now: a pilot project to create an EU Health Space should be initiated through Horizon Europe funds.

Conflict of Interest

None. ■

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