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Ethical Dilemmas in the Time of COVID-19: mapping, understanding, building systemic resilience

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Preface / word of caution

This dissertation contains smileys.

When I realized this fact, I had very mixed feelings. On the one hand, I have spent many years of my life trying to fight my imposter's syndrome and to appear competent, proper, respectable – and in this sense, honestly, having smileys in your PhD dissertation sounds a bit like shooting yourself in both feet before running a marathon. On the other, at some point during my 'chronic' PhD career I realized one simple fact: the point is not **appearing** competent, proper, and respectable – it's all about **being**.

I had a non-linear career path and a non-linear life. I didn't end up in a PhD program because I didn't know what to do after my master's. I had a nice job which I enjoyed a lot, a permanent position, in my country, among the mountains I belong to, surrounded by friends and family. Yet, I decided to leave all that behind and leave. Why?

Because I have this weird belief that we should leave the world better than we found it, if we want to leave it with some sense of accomplishment – and live with some sense of purpose. And I'd like to have both, sooner or later.

That's why at some point I realized how badly I wanted to do a PhD – to do *research,* to bash head-first against the boundary between what we know and what we don't, trying to move it at least a tiny bit. I went back on the books and put together a nice research proposal, and after about 15 failed applications and 5 years, here we are: I have managed to finish something *completely different* from what I originally planned.

It's been a nice ride. I've learnt tons of stuff about the world and also about myself. I still don't know if I managed to leave at least a dent on that famous boundary I was mentioning above – but one thing I know for sure: I had tons of fun in the process.

That's when I realized that nowhere it is written that something rigorous or serious or important or well done should be also boring. Even more so: doing research can rough you up real quick and real bad, if you don't pay attention. And having fun in the process is an excellent way to keep sane. When I understood this lesson, that 'fun' – which is a part of my nature – is actually good, I abandoned all the fuss about 'appearing' and I actually started enjoying 'being'. This improved my quality of life, my creativity, and hopefully the quality of my work. Hence, all in all, smileys (or funny owl pictures in each and every presentation) are not that bad.

Concluding this preface/word of caution, the bottom line is: I tried to put together something good, solid, entirely open, and as less boring as possible. Have fun 😊

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0. Abstract

The outbreak of COVID-19 has posed unprecedented challenges to public health officials and ethicists alike. The response to the pandemic has forced us to grapple with a number of ethical issues that have arisen in the context of quarantining, risk communication, and patient care. In this dissertation, I aim to explore some of the emerging ethical issues that have arisen during the pandemic and to identify possible solutions to these ethical dilemmas. I begin by providing an overview of the ethical principles that have been invoked in debates about the ethics of quarantine and risk communication (Chapter 2). Chapter 3 details a novel approach to retrieve and map large amounts of literature applying smart iterative search strategies and natural language processing (NLP). In Chapter 4 I further develop the approach detailed in Chapter 3 and apply it to map the large body of literature on emerging ethical issues connected to COVID-19. This NLP-based analysis provides a comprehensive overview of the current state of research on emerging ethical issues in COVID-19. Next, Chapter 5 presents the protocol for PubliCo, a study/intervention that aims to improve bidirectional risk and crisis communication between public health officials and members of the public, incorporating active social listening methodologies. Chapter 6 explores 'the dark side' of social listening, i.e. passive social listening, in order to conduct an empirical mixed methods study aimed at understanding the magnitude and the meaning of digital conversations of no-green-pass groups. Chapter 7 presents the protocol for a state-of-the-art approach for collecting and analysing patient narratives, through which many novel and unforeseen issues can be pinpointed, especially those connected to fairness in healthcare and communication. Finally, Chapter 8 offers a systematic ethical framework for risk and crisis communication, based on the findings of this research, that can be used to guide the design, governing and evaluation of communication actions in current and future crises.

1. Introduction

Introductions are made either to annoy the eager reader, willing to jump straight to the content, or to explain the issue at stake, declaring the implicit assumptions and positions, providing a map to apprehend, contextualize and navigate the content. As my ambition is the latter, I will try to be concise and poignant.

Context

Apparently Nassim Nicholas Taleb has grown an increasing irritation about the media referring to the COVID-19 pandemic as a 'black swan event' (Avishai 2020). Rightfully so.

'Black swan' is a concept that the mathematician introduced in his eponymous book, published in 2007, to describe events that are rare, hard to predict, and with the potential of generating catastrophic impact on our societies (Taleb 2007). As argued in Chapter 8 of this dissertation, COVID-19 does not qualify – at all – as a black swan event. This pandemic and its consequences were neither unforeseeable nor unforeseen, as the possibility of spillovers due to the destruction of natural habitats has been on the radars of science for quite a while. It is not an unprecedented event: SARS (severe acute respiratory syndrome) in 2003, H5N1 avian flu in 2004, Zika in 2015 are just three examples of recent epidemic outbreaks that could have turned into pandemic nightmares.

One thing is true, however, when applying the 'black swan model' to describe COVID-19: it proved its potential to generate catastrophic impact on our societies. That is the core message of Taleb's work on uncertainty: black swans are structurally hard to predict. But we can build preparedness strategies. We can study past (or present) catastrophic events, understand what did work, what did not, and plan better. Not only: we can (must – but that's already ethics) embed such antifragility plans in the workings of our societies, in order to try mitigating the consequences of the next existential threats we will face – or cause.

Aims

My personal taste for existence – and for preparedness as a strategy to ensure its continuation – is the red thread connecting the work presented in this dissertation. This is the direction in which I tried to systematise what started as a rapid response to an urgent emerging problem: identifying the core issues it presented; understanding their dynamics; proposing solutions. There was no research plan, when I started writing the first paper of this collection. Or better, there was one – completely different, on a different topic. So rather than dutifully working my way through a list of specific questions, emerging from a general question, contained in a duly approved research plan, I had to improvise a bit. Which, indeed, is a good lesson, and a difficult one to digest: on the one hand, we are all tempted to jump on a new, shiny, and well-funded bandwagon, but we are ashamed to admit that is the case, that our drives are shininess and funding; on the other, research (action-oriented research) should be intended as 'a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes', seeking to bring together theory and practice, empirical evidence and reflection, in a participatory process trying to find 'practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities' (Reason and Bradbury 2008, 4). In other words, in a context of pressing urgency, there are reasons that are much better than the aforementioned bandwagon to switch focus quick and fast, trying to understand new problems first, then, to invent the solutions – when solutions are possible. This notion of research (action-oriented research) is what drove me through the entire process.

I am a philosopher by training and an ethicist by choice, therefore that is the lens through which I observe the world, and therefore that is the focus of this dissertation. That is the kind of problems I am trained to identify, dissect, taxonomize, understand, and possibly fix. It begins in medias res: there is a new big issue to which we are (culpably) unprepared. How did it happen? Why are we setting up quarantines and lockdowns all over the world, asking people to stay put at home, and enforcing this recommendation? Do we have any previous experience or theoretical reflections on this? If so, how can they help us navigating this new issue, making the least worst choices? Quarantine and isolation were just the tip of the iceberg, during the COVID-19 pandemic. Even just mapping all the emerging ethical issues took time and was less straightforward than one would expect. So, what do we focus our work on? How can we decide which ones of the many emerging issues – spanning from limitations of personal freedom to allocation of scares resources, from compression of privacy spaces to information ethics – are the most urgent and more pressing to try sorting out?

Methodological approach

In this sense, my methodological toolbox helped. I am a weird kind of philosopher: I like to dip my fingers in many different jars of methods marmalade, ranging from programming languages to qualitative research. Python-based natural language processing proved crucial to map large amounts of non-structured or semi-structured textual data in short amounts of time; some degree of familiarity with surveys, descriptive and inferential statistics is the cornerstone of large sections of the studies described in Chapters 5 and 6; qualitative analysis and thematic analysis are fundamental tools for what described in Chapter 7, and complementary for Chapters 5 and 6. Lastly, some understanding and command of 'mixed methods' proved paramount. Mixed methods means more than just 'using multiple methods to answer one research question': in line with Meissner and colleagues, mixed methods are well suit for 'research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences', and entail a) utilizing multiple methods; b) integrating both the methods and the conclusions to draw on the strengths of each; c) framing the investigation – so, the design, the methodological layout and the interpretation of the conclusions – within philosophical and theoretical positions (Meissner et al. 2011). Mixed methods are particularly well suited for dealing with ethics, because of the very nature of ethics: an attempt to describe and develop moral reflections on human phenomena, intrinsically multifactorial, intrinsically needing to incorporate data and theory from different disciplines.

Conceptual palette

Throughout this work I make extensive use of some key philosophical concepts. In order to provide a clear reference framework, I proceed with their definition and disambiguation, so that their use is understood consistently across this dissertation.

Fairness and justice

Fairness and justice are two deeply intertwined concepts. I intend them as formalized by John Rawls (Rawls 2005a; 1985). According to Rawls, democratic societies can be conceived as intricated systems of social cooperation. Justice, intended as fairness, is their primary deontological goal, therefore justice must be understood on a political – and practical level, not only as a metaphysical concept. Two main tenets drive its interpretation – and implementation:

1. *Each person has an equal right to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with a similar scheme for all.*

2. *Social and economic inequalities are to satisfy two conditions: first, they must be attached to offices and positions open to all under conditions of fair equality of opportunity; and second, they must be to the greatest benefit of the least advantaged members of society (Rawls 1985).*

The theoretical underpinning is the tension between liberty and equality – and the attempt to harmonize that tension. On an individual level, social cooperation entails both benefits and burdens, as it entails a negotiation between the freedoms of different individuals, which by definition are not aligned. Justice as fairness results therefore in a contract theory that allows to navigate these tensions in the pursuit of common goods, as defined by rational persons (Rawls 2005a, 16, 32).

Efficacy

My understanding of 'efficacy' and the way I use this concept throughout this dissertation is based on the work of Nancy Cartwright (Cartwright 2009). There is a connection – and often some confusion – between efficacy and effectiveness: "efficacy is what is established about causes in RCTs – randomized controlled trials. Effectiveness is what a cause does 'in the field'" (Cartwright 2009). Efficacy, efficiency, and their interconnection are of special relevance when arguing about evidence-based measures: if efficacy measures the ability to produce benefit in an ideal context, and effectiveness measures the ability to produce benefit in real life conditions, 'boots on the ground', what shall we aim for, when discussing evidence based public health measures? Efficacy or effectiveness? As Cartwright argues, "efficacy is to contribute evidence for effectiveness". This is the logical and epistemological order: ideally, when deciding whether to deploy this or that measure, we need to know how efficient it is in an experimental context, and that information build evidence for (or against) its effectiveness in real life scenarios. Effectiveness, in sum, is a function of efficacy and context (e.g: how a given measure, which is efficient in an experimental controlled context, will perform in a scenario including much more variables). This distinction is especially relevant in pandemic management: we need to keep in mind that efficacy is what we are looking for, but it is not at all the endpoint of the process. It is a brick, a foundational and necessary one, but it is not a sufficient condition for deploying a truly evidence-based measure.

Transdisciplinarity and participation

The concept of transdisciplinarity was first formalized – in a rather peculiar way – as a posture in which knowledge is produced through the contribute of multiple disciplines and multiple stakeholders, in cooperation to jointly study multifaceted problems, rather than in juxtaposition to singularly study some of its aspects – "a space for synthesis across, between and beyond disciplines" (de Freitas, Morin, and Nicolescu 1994). While some articles of the eponymous 'Charter of Transdisciplinarity' feel peculiar (e.g: "Transdisciplinarity constitutes neither a new religion, nor a new philosophy, nor a new metaphysics, nor a science of sciences") (de Freitas, Morin, and Nicolescu 1994, art. 7), the overall epistemological horizon is valid: as life is complex, focussing only on one specific angle of an issue through the lens of one specific discipline cuts out a lot of its complexity, and leads to losing the global perspective. An example in this sense, topic in which transdisciplinary approaches have become increasingly widespread, is environmental change. In fact, transdisciplinarity is the approach of choice of the Belmont Forum, an EU funded international partnership of research institutions, regional consortia, and founders committed to gathering and generating systemic knowledge on global environmental change and sustainability. According to the Forum's white paper, the first and foremost element needed to address complex global challenges is "a transdisciplinary approach enabling inputs and scoping across scientific and non-scientific stakeholder communities and, facilitating a systemic way of addressing a challenge. This includes initiatives that support the capacity building required for the successful transdisciplinary formulation and implementation of research actions" (The Belmont Forum 2016). In a nutshell, complex systemic problems are multifactorial, and need cross-cutting strategies to develop answers. This includes cross-boundary contamination of disciplines and methodologies, and the participation of lay stakeholders, beyond the academic community. This horizon applies well to the issues discussed in this work.

Participation, however, is a complex topic. Involving people from the lay public in a research project implies taking seriously into account their views and perspectives, which can pose ethical challenges. A famous (and spurious) quote from Henry Ford is a good starting point to understand the issue: "If I had asked people what they wanted, they would have said faster horses" (Vlaskovits 2011). Bringing people in a research project – as stakeholders, not merely as participants or data providers or data classifiers – implies taking into account their views on ethical issues, which might or might not be aligned with the academic consensus. When reflecting on Ford's spurious quote and on the role of individuals in generating innovation, Vlaskovits notes that two main positions come to an unavoidable clash: "one side vehemently argues the merits of innovating vis-à-vis customer feedback; the other argues that true innovation is created by singularly gifted visionaries who ignore customer input and instead manufacture innovation based solely on their prophetic vision for a better future" (Vlaskovits 2011).

Out of metaphor, the question is: what is the value of people's voices – and knowledge – when we pursue innovation in the form of new tools and approaches intended to manage processes with societal and ethical significance? What if, instead of 'faster horses' people call for something that the academic consensus considers morally despicable – e.g.: denying intensive care to migrants or homeless people, as 'they do not contribute to society's welfare'? These are speculations, but realistic and plausible ones.

From my standpoint, the question is a faulty one. First of all, because it's hard to reduce the aim of this process to something clear-cut and measurable such as 'becoming the dominant car manufactory in terms of sell-out, revenue, and what not'. Ethical innovation should be both people-centred and morally sound, there is no possibility for either/or trade-offs, and this specificity of the process should indeed be part of the aims of ethical innovation – in this sense, we can consider ethical innovation as a process-driven activity. Second, the question is faulty because, following Rawls, tensions between different (reasonable) opinions are a core feature of pluralistic democratic societies, not something one can avoid or dismiss. Ethics is precisely the result of the discourse between and among these opinions.

The strength of Ford's biggest innovation, mass production through assembly lines, was reducing to the bare minimum the production cost of one standardized car, "available in any color… so long as it is black". It was the opposite of people-centredness. Participation is the opposite of standardization. It is messy, by necessity and definition, and in the short run it is the opposite of efficiency – 'efficiency', not efficacy. But this messiness is, again, a normal and healthy feature of pluralistic democratic societies. Therefore, the issue is not to avoid it or to reduce it or even to deny it, but to find effective ways to structure the dialogue among, with, and on these different voices, integrating them in a theoretically solid reflection. It's a thin line to walk on, but an unavoidable one.

Citizen science

Citizen science is a recent – but rather consistent, nuanced, and structured – way to foster public participation in scientific efforts (Vohland et al. 2021). Citizen science is (still) a concept with fuzzy borders, defined in different ways by different research institutions, funding agencies, and associations of citizen scientists (Eitzel et al. 2017). The definition I adopt in this work is that proposed by Heigl and colleagues (Heigl et al. 2019). It entails six main markers:

1. Scientific rigour, in terms of research question, methods, and rationale for developing new methods or new knowledge;
2. Collaboration: active involvement of the citizen scientists in the research process, and added value of the collaboration for all the parties involved (in this sense, for instance, an opinion poll does not qualify per se as citizen science);
3. Open science: all the data (not just the publications) resulting from a citizen science project should be openly and transparently available (provided that there are no ethical issues in releasing the datasets, or that these issues are managed);
4. Communication: active bidirectional communication between researchers and citizen scientists in structured dialogue spaces or communication strategies;
5. Ethical standards: compliance with ethical standards, inclusiveness, clear information on data policy and data governance;

6. Data management: a solid data management plan should be defined prior to data collection to ensure consistent, transparent and clear quality standards when pooling, storing, accessing, sharing, and reusing data.

As highlighted by Heigl and colleagues, citizen science is an important instrument for the democratization of science production, and it has "amazing potential as an innovative approach to data gathering and experimental design, as well as an educational and outreach tool" (Heigl et al. 2019).

Knowledge production as a process

My notion of knowledge production is highly connected with my understanding of action-oriented research: "a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities" (Reason and Bradbury 2008, 4). In this sense, the process of knowledge production changes quite radically its shape and its actors.

There are two distinct issues in nailing down this definition: 1. the tension between theory and practice, and 2. who is actually involved in the process of knowledge production.

Regarding the first point, the issue can be summarized as: "when we decide to combine research and action, don't we lose theoretical acuity"? This critique has several good rebuttals. First, the distinction between theory and action is a historical product of cartesian and post-cartesian philosophy. A position criticized, namely, by Kant's Critique of Pure Reason, by Kierkegaard's phenomenology, and by pragmatists like Peirce and Rorty (Gustavsen 2003). Summarizing, the role of theory "is not only to help us make a picture of the world as it is, but also – and of greater importance – actually to make us see how the world could have been. Understanding is consequently something that plays itself out between three reference points: theory, practices as they are and practices as they could have been" (Gustavsen 2003).

Regarding the second point, it is clear that knowledge having the aim to generate a positive impact on society should be co-produced by society. Going back to Rawls' definition of fairness, inclusivity, participation, and co-design are not options or nice-to-have features. 'Society' sounds rather broad and a-specific, though. Even more so, assuming a distinction between 'academia' and 'society' seems to imply that the former is something distinct from the latter – which is not the case. I will now delineate *in nuce* the phases of what I understand as a knowledge production process, highlighting current and future opportunities for the democratization and opening up of the process to citizen scientists and societal stakeholders beyond the academic community. As a general note, the definition I provide result from my experience during the course of this work, but try to be at the same time precise and generalizable, so that it is possible to translate and transfer them to other topics, contexts, and disciplines.

Definition of strategic priorities

Research efforts begin with the definition of questions, issues or open problems connected to common themes or topics (Ertmer and Glazewski 2014) – i.e. of a research agenda. A research agenda specifies the focus of scientific activities and orients them, both in the long and in the short run. The definition of a research agenda is therefore a crucial activity in 'defining the direction of progress' – a broad concept, encompassing the entire scientific pipeline, from the conception of research projects to the implementation of the resulting innovations in real life.

Although some excellent examples of participatory processes in the definition of strategic priorities do exist, e.g. in planning the use of land and soil (INSPIRATION 2015), as of today these activities largely remain top-down. Beyond abiding to Reason and Bradbury's tenet, incorporating the voices of other stakeholders, institutional (e.g.: local or regional administrations, associations, …) or non-institutional (e.g.: citizen science groups, lay public) has three main advantages:

- A participatory approach to the definition of research agendas is a first and fundamental step to reduce the fracture between science and society which is generating mounting waves of distrust (Van De Walle and Six 2014);
- Involving the public in the definition of research priorities increases the likelihood of the public contributing to research activities stemming from said priorities;
- The implementation of innovations requires the public to accept said innovations. Research resulting from participatory (and participated) processes is more likely to be accepted by the public, and thus to have an easier and faster transition from the academic setting to real life applications.

Development of research projects

A research project might or might not target items from a research agenda. While having a defined research agenda is certainly of use and helpful to drive scientific development in certain areas which are perceived as critical, it should not be the only driving force.

Research agendas take time to be defined, especially if this includes a participatory component; therefore, some degree of freedom in developing new ideas and new concepts – in terms of topic or methodology – should not be disregarded, as it creates a flexible space not only for rapid responses, but also – and importantly – for creativity. There is a growing body of literature about creativity in research, highlighting the importance of detours along unplanned lines; the possibility to join creative processes with methodological rigour; the role of creativity in knowledge production; the contribute of creativity as a 'glue' for inter- and trans- disciplinary research activities (Ulibarri and Cravens 2019; Runco 2014; Glăveanu (eds.) 2016; Wegener, Meier, and Maslo (eds.) 2018). The development of a research project is a fundamentally creative process, in which the role of creativity is precisely that of charting the route from the known to the unknown through the creative use of a rigorous methodological palette.

The definition of a research project comprises therefore a 'storming' phase, during which ideas are poured on the table in an unstructured way, and a 'norming' phase, during which these ideas are filtered, chosen, structured, interconnected and organized in a consistent concept. There is space for participatory approaches during the definition of a research project, specifically during the 'storming' phase: in this context the ideas and voices of citizen scientists can effectively contribute new perspectives and help defining new methodological approaches, or new implementation strategies for existing and consolidated methods.

Prioritization and allocation of funds

Research projects are typically funded through project specific funding by public or private funding agencies. Typical evaluation criteria for the prioritization and selection of projects include scientific quality of the project; relevance; feasibility; originality; credibility, qualifications, and previous work of the researchers involved. In recent years multiple funding agencies have started to incorporate the DORA principles in defining and applying evaluation criteria, such as transparency of the criteria, considering the impact of less conventional research outputs (e.g.: software, datasets, …), avoiding to use publication metrics (DORA 2012). Prioritization and allocation of funds could and should consider citizen science components; moreover, it would be interesting for funding agencies to experiment with involving citizen scientists also in the prioritization process, i.e. asking to citizen scientists to rate and prioritize research projects, in a way similar to what academic reviewers do.

Research activities

Once a project is structured, defined, and funded, it is time to actually do the thing. Research activities include defining a phenomenon and setting the stage through reviews of existing literature, using traditional or innovative approaches; crafting and testing data collection techniques; analysing and interpreting new or existing data; producing theoretical reflections, integrating results and theory.

Research activities can easily incorporate participatory processes. Again, the crucial thing is to keep in mind that 'participation' means more than just providing data, as in the definition of citizen science provided above. Citizen scientists can participate in the validation and testing of data collection platforms, in the data collection itself, in the analysis, and in the interpretation. In this sense the reflection developed in Chapter 8 of this work on the PHERCC ethical values (openness, transparency, inclusivity, understandability, privacy) can be considered as a function of the ethical horizon that governs and informs citizen science for how I understand it. In the context of research activities these values have a guiding force in defining how the data structure should be shaped, and why. This stack of values, once implemented in research activities, allows citizen scientists to access, understand, and reflect upon a dataset.

Dissemination of research outputs and deployment of innovation

Dissemination of research output shall be understood in a broader sense than 'publishing the papers'. Dissemination is a global effort to ensure that the research work generates further scientific, political, and social impact – therefore, scientific publications are just a piece of the puzzle. The research process produces information, data, tools, notes, research journals, and ideas in a raw form – using a biological metaphor, this constitutes the DNA of the research output: a messy mass including a lot of 'noncoding DNA' mixed and intertwined with the codifying information contained in genes: exons, promoters, regulatory elements, introns... DNA does not act directly on its surroundings: in order to do so, it needs first to be organized and transcribed to RNA by RNA polymerase enzymes. RNA filaments are – in metaphor – the informational output of a research project: this includes research papers, but also, and importantly, public releases of preprints, software, datasets. This 'transcribed information' – out of metaphor, information organized, structured and parsed – constitutes the primary output of the research project, i.e. what leaves the nucleus of the cell (the research team) and enters the cytoplasm. Only when the DNA is transcribed into RNA and enters the cytoplasm (the broader academic and societal context) it becomes available to ribosomes, which can translate it into long and complex sequences of amino acids joined by peptide bonds: proteins, i.e. tools having active and practical functions in the organism: structural components, antibodies, enzymes, … Out of metaphor, in actual innovation (technologies, policies, tools, …) able to have an impact on society.

If research aims to have a concrete (and ideally ameliorative!) impact on society, dissemination should be planned taking into account the whole process, and keeping in view this aforementioned aim. That is why dissemination should mean much more than 'publishing the papers' (and increasing one's H index in order to maximise the chances of getting that next grant). Every bit of information which has internal consistency and might have practical significance should be 'transcribed to RNA' and released under an open access license, accompanied by metadata ensuring adherence to the FAIR data principles: findability, accessibility, interoperability, reusability (Wilkinson et al. 2016).

Dissemination, as detailed as far as now, might look very disconnected from participatory approaches. Back to the PHERCC stack of ethical values (openness, transparency, inclusivity, understandability, privacy – see Chapter 8): the mere availability (under open access licenses) of preprints, publications, datasets and software accompanied by FAIR compliant metadata, satisfies the requirements of openness and transparency. In order to pursue a participatory approach, this is not sufficient – understandability is key. Making research output into something understandable (and possibly engaging) for the wide public is a science itself (Fischhoff and Scheufele 2013). As such, it requires the contribution and input of trained professionals to function – a function that should be considered already in the definition of a research project.

Ethical horizon

Although an exhaustive discussion of the transition (or rather: *translation*) from moral philosophy to applied ethics is beyond the scope of this work, I nonetheless deem it appropriate to devote a few lines to the topic and my specific position on the issue.

Due to its nature, the ethical horizon of this work is inherently duplex, both deontological and principlistic. In my view this is not contradictory, but rather a pragmatic solution. In this sense, I intend deontology as the theoretical moral standpoint to which I refer, and principlism as a way to translate deontological tenets to applied ethics.

The deontological guidance is layered. The foundation is provided by the work of Immanuel Kant, in particular by the first formulation of the categorical imperative contained in the *Grundlegung zur Metaphysik der Sitten*: 'Act only according to that maxim whereby you can at the same time will that it should become a universal law' (Kant 1785, 30). The second layer, providing an initial step for the translation of Kant's categorical imperative into the field of public health ethics, consists in John Rawls' reflection on political liberalism, on the definition and role of justice in a liberal democracy, and on its characterization through the principles of liberty and of equality (Rawls 2005a; 1985; 2005b).

The principlistic approach, aimed at further translating the Kantian foundation into applied ethics – in this case, risk and crisis communication ethics, which in turn I consider as a subset of public health ethics – is original work, fully developed in Chapter 8. It consists of five principles: openness, transparency, inclusivity, understandability, and privacy. Ideally, developing risk and crisis communication actions based on these principles allows to pursue justice as fairness, which in turn allows to pursue Kant's categorical imperative.

I believe it is important to stress the fact that I do not consider this layered approach as some sort of threshold deontology (Moore 1997, chap. 17) in which the fallback strategy is principlistic instead than consequentialist. The principlistic approach is derived from the deontological foundation and aims to translate deontology into practice, it is not a first line option from which one could or should fall back if need be.

One important final remark regards the utilitarian/consequentialist approach which in several countries has dominated the early phases of the pandemic management. On these grounds, the imperative has been to 'protect the population' (The Swiss Federal Council 2020). While the meaning of 'protect the population' has often remained implicit, it has been widely interpreted and understood as 'strive to reduce pandemic metrics such as new cases, crude mortality rate, R_0, and so on, while adopting the least burdensome measures'. A given measure or action is good when its consequence is to reduce said metrics, else it is bad.

I believe this (implicit) moral horizon, whose justification has been built on emergency arguments, is simplistic and naïve to the point of being unacceptable. 'Protecting the population' means much more than that in a liberal democracy – or it should mean much more than that. Most importantly, that implicit moral horizon should have been unpacked and made explicit, clear, and transparent.

Epistemological horizon

Concluding this introduction, one last short word on what I intend as 'knowledge' and 'knowledge generation' throughout this whole work. As it is largely exploratory, the epistemological trendline is largely based on abductive reasoning. In this context, following

Pierce and Lipton, I intend 'abductive reasoning' as 'inference to the best explanation'. In a nutshell, inference to the best explanation is the process allowing to move from evidence to inference – distinguishing actual from potential explanation – producing a pool of potential explanations, from which the best one is inferred (Lipton 2004). This is not – at all – a recusation of Popper's falsificationism. It is simply the most pragmatic epistemological horizon one can adopt in a rapidly evolving context which calls, first of all, for charting and mapping, rather than for developing theories on well observed phenomena, to be empirically verified or falsified.

2. Quarantine

Discrimination, quarantine and isolation were the entry point, the first issues of ethical relevance the pandemic challenged us with. Quarantine and isolation are an efficient way to break infection chains, and a meaningful strategy to apply, especially at the beginning of a pandemic, when options for prevention and treatment of are still limited – but quarantine and isolation come to a cost: a significant limitation of personal freedom. Is this limitation acceptable? Under which conditions, and with which caveats? This is what Chapter 2 deals with: introducing the scenario of the COVID-19 pandemic, presenting these first emerging ethical issues, and analysing them in an historical dialogue with the Eyam Plague and its management, read in light of Ross Upshur's Four Principles for the Justification of Public Health Intervention, and of the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights. (COI declaration: written at the very beginning of the pandemic, while being subject to quarantine measures after returning to Switzerland from Italy).

COVID-19 and The Ethics of Quarantine: a Lesson From the Eyam Plague

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Abstract

The recent outbreak of the SARS-CoV-2 coronavirus is posing many different challenges to local communities, directly affected by the epidemic, and to the global community, trying to find how to respond to this threat in a larger scale. The history of the Eyam Plague, read in light of Ross Upshur's Four Principles for the Justification of Public Health Intervention, could provide useful guidance in navigating the complex ethical issues that arise when quarantine measures are put in place.

Keywords

History of medicine, history of epidemiology, Eyam, plague, 2019-nCoV, public health ethics.

Introduction

The recent outbreak of the SARS-CoV-2 coronavirus is not an exclusively medical issue. The history of medicine and contemporary reflection clearly teach how an epidemic may have deep and sometimes radical social implications (Cohn 2002). After all, it is sufficient to keep an eye on the news of the day to recognise the fact: in addition to information on the progress of the disease, on the efforts of the scientific community to find a cure, or on the conditions of cities under quarantine, since the beginning of the outbreak newspapers from all over the West reported unfriendly, suspicious and sometimes openly racist attitudes towards people of Asian origin (Hussain 2020; Iqbal 2020; Lindrea and Gillett 2020; Ling 2020). The Twitter hashtag #JeNeSuisPasUnVirus, "I am not a virus" has become—the pun is not intentional, but hard to avoid—viral, used by thousands of users around the world to raise the level of public attention on the upsurge of xenophobia, "justified" (quotes are a must) by the fear of contagion. As the outbreak progresses and hits new countries, accompanied by its toll of panic, the same irrational dynamics could easily regard people with different origins. After the initial phase of virus entry into a new country, other divisions emerged, in this case not based on ethnicity but between different social groups, accompanied by the same load of suspicion and distrust. In the USA face masks have been resemantized from personal protective equipment to political symbols and statements, visually marking the division between “smug liberals” and “reckless republicans” (Lizza and Lippman 2020; Vetterkind 2020). In Italy, during the hardest phase of the lockdown, categories allowed to leave their houses, like dog owners, have been heavily stigmatized by so-called “balcony watchdogs”, and multiple sources have reported dogs killed by poisoned bites (BresciaToday 2020; Berton 2020; La Gazzetta del Mezzogiorno 2020). It seems that, together with the death toll and the incredible strain on health care systems, this pandemic brought us a steady corrosion of our societies’ social fabric. Although reactive institutions and social order are helping to avoid radical episodes, it is inevitable to note sociological affinities with the generalized and execrable suspicion towards entire human categories—Jewish people—that characterized many Black Plague outbreaks since 1348 (Finley and Koyama 2018). It is mandatory to point out that, in parallel with these divisive processes, many initiatives of diametrically opposite sign have punctuated lockdowns: togetherness has been expressed all over the world singing together from the balconies, applauding health care staff, volunteering for running errands for elders or other particularly vulnerable people, and so on. Nevertheless, social corrosion seems to be a stable companion of epidemics and quarantines, and as such an important side effect to consider, study and counteract.

This paper aims to offer two reflection standpoints for reflecting on whether and how it is possible to put in place ethically acceptable containment measures in the context of epidemics. One is historical, represented by the Eyam Plague, and one theoretical, offered by Upshur's Four Principles for the Justification of Public Health Intervention and by the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights.

Image 1, Plague Cottage: former residency of George Viccars, first victim of the Eyam Plague

Eyam Plague

A few years ago I had the opportunity to visit the Peak District, in the UK. In an isolated Derbyshire valley I found the village of Eyam, sadly known to anyone with at least some familiarity with the history of epidemiology. In September 1665 the village was hit by a very serious plague epidemic, which decimated the small community: in October 1666, at the end of the epidemic, 257 of the approximately 700 people living in Eyam had died (Whittles and Didelot 2016).

According to the tradition, based on local chronicles (Wallis 2006) and stratified in various nineteenth-century literary narratives, the contagion was caused by a box of clothes imported from London by Alexander Hadfield, the village tailor. A few days after receiving the package, probably infested with infected fleas, George Viccars, Hadfield's assistant, died of the plague. Although some modern epidemiological studies accept this version (Massad et al. 2004), the real cause of the epidemic remains unclear: several authors believe, for example, that the outbreak of the epidemic was rather caused by an enzootic reservoir of wild rodents (Coleman 1986).

One point on which nineteenth-century chronicles and contemporary studies are in agreement is the management of the epidemic by the citizens of Eyam, at least peculiar for the time. Although the mechanics of the contagion were not clear, the first response to plague epidemics in the seventeenth century was often quarantine. This measure was detested by those who were subjected to it, and often violently opposed: in this sense, among the many, can be appreciated the contemporary testimonies of Samuel Pepys, an eyewitness to the Great Plague of London in 1665–1666 (Pepys 1893, vol. IV).

In London, Pepys writes, the limitation of contagion required drastic measures: "a watch is constantly kept there night and day to keep the people in, the plague making us cruel, as doggs[sic], one to another" (Pepys 1893, vol. IV). It is a sentence that deeply echoes Hobbes' "homo homini lupus", depicting a rapid and radical disruption of social fabric, strong enough to cast back London to that state of nature intended as "bellum omnium contra omnes".

In Eyam, however, things took a different turn: the parish priest William Mompesson persuaded the local population about the need to establish a cordon sanitaire, placing the village in voluntary quarantine to protect other communities in the region from contagion (Wallis 2006).

The concept of "voluntary quarantine" is of particular interest: "quarantine", from the Italian word "quaranta" was a sanitary measure introduced for the first time by the Most Serene Republic of Venice in 1377, during a plague outbreak in Dubrovnik and on the Dalmatian coast. Plague was spread by ships sailing from the eastern Mediterranean, and thus "if there was suspicion of disease on the ship, the captain was ordered to proceed to the quarantine station, where passengers and crew were isolated and the vessel was thoroughly fumigated and retained for 40 days” (Tognotti 2013). Historically, all over Europe quarantine was always imposed, and often enforced with firm measures. This is the reason why the case of Eyam is so peculiar: the quarantine was not imposed by an external authority, but the result of a persuasion process—and of a negotiation process—between William Mompesson and the local residents. As Sharp reports, “When the plague become worse, his wife besought him to leave the place, but he refused to do so. Moreover, he induced a number of the villagers, who wished to leave, to abandon their intention, by pointing out to them that they would carry the disease with them, and be a danger where ever they went. At the same time he wrote to the Earl of Devonshire, stating that the people would stay in Eyam if they were supplied with the necessaries of life” (Sharp 1898).

I remember two of the most interesting points during my visit to Eyam. The first: Cucklett Church, a "church without a church". Concerned that mass might contribute to spreading contagion, William Mompesson began saying mass outdoors, at this limestone platform (Sharp 1898). The second: Mompesson's well, an exchange point on the northern border of the county, used by residents of neighbouring towns to leave food and medicine to the quarantined community (Sharp 1898).

Some contemporary authors have hypothesized that in reality these measures may have contributed to increasing the mortality rate among the citizens of Eyam: according to Massad et al. “the hypothesis that confinement facilitated the spread of the infection by increasing the contact rate through direct transmission is plausible” (Massad et al. 2004); nevertheless, it remains clear how this “voluntary quarantine policy was humanitarian in intent; it was logically consistent with prevailing knowledge of plague, and it was pursued with great courage in the face of huge losses”(Coleman 1986).

The plague of Eyam ended in October 1666, leaving behind 257 deaths and a series of questions, some of them of a markedly ethical nature. What measures should be taken to try to limit an epidemic? What are justifiable, and if so, by what principles? Where to draw the line between the rights of individuals and the interest of communities? How to manage the different (and competing) interests of neighbouring communities?

Disentangling causes and effects?

In order to understand what causes this corrosion of the social fabric that characterized most of the epidemic outbreaks (but not Eyam's), it would be important to try untangling what can be imputed to the epidemic itself, and what to quarantine measures. In a recent review on the psychological impact of quarantine, Brooks et al. tried to summarize how this kind of measures impacts on people's psychological health (Brooks et al. 2020). Considering recent epidemics and pandemics (2003–2019) they identified five stressors during quarantine (duration, fear of infection, frustration and boredom, lack of supplies, lack of information) and two post-quarantine stressors (finances and stigma).

Looking to this list it is immediately clear how deeply these issues are intertwined. "Fear of infection", for instance, is clearly caused by an ongoing epidemic, even if quarantine measures can make people more aware of it and somehow hasten it. In this context we can definitely say that more research is needed, maybe comparing ethnographic studies conducted in places where quarantine measures were not imposed during the COVID-19 pandemic versus others conducted in quarantined areas.

What we know for sure is that epidemic outbreaks and quarantine measures to some degree contribute in creating a climate of fear, insecurity, and competition for scarce resources, resulting in the polarization of existing divisions. But, again, not in Eyam. Was it an idyllic village with no pre-existing differences that could be exacerbated by these phenomena? Not quite: as reported by Wallis, Mompesson had to craft and implement his plan together with Thomas Stanley, previous rector of Eyam (and still supported by many inhabitants) until his eviction for non-conformity, dating to 1662 (Wallis 2006). At least one, very deep social division based on religious credo was there, ready to blow. But it did not.

Principles of quarantine ethics

To date, the reflection on public ethics and ethical response in the context of epidemics and pandemics revolves mainly around four approaches: deontological (or Kantian), utilitarian, principlist and casuistry (Coughlin 2006). Ross Upshur proposed an interesting epidemiological adaptation of the standard principles of Beauchamp and Childress, introducing a framework specifically designed for situations where quarantine measures are necessary:

1. Harm: the restriction of the freedoms of individuals or groups can only be justified if it is indispensable to avoid causing harm to others;

2. Least restrictive or coercive means: any action justified by the first principle should always use the mildest possible measures. In other words, education and discussion should precede prohibition or regulation;

3. Reciprocity: societies within which public health measures are taken must be prepared to compensate for any inconvenience caused to individuals or groups subject to such measures;

4. Transparency: all stakeholders affected by public health measures must be involved in the whole decision-making process, and the decision-making process must be as clear as possible (Upshur 2002; 2003).

The history of the Eyam pestilence proves to be a paradigmatic case, bearing in mind the limited medical knowledge available at the time, when read in the light of Upshur's approach:

1. The limitation of the freedom of movement of the citizens of Eyam, through the establishment of the cordon sanitaire, was justified by the risk of spreading the contagion in the region;

2. The quarantine measures used were in fact concerted, relatively mild and accompanied by information on the prevention of contagion (such as outdoor masses);

3. The surrounding villages provided continuous material support to the population of Eyam;

4. In contrast to what happened in London—according to Pepys' diaries—quarantine decisions were not imposed in Eyam, but were rather discussed openly within the community.

The empirical test of theories in the field of public health ethics is often a problematic matter, if not a daunting task. But still it is needed, in order to assess the validity of a specific approach in managing complex situations in which decisions are critical and come with a price, often a heavy one. That is why the history of the Eyam plague is so valuable: because it gives some hints about how things could go, adopting a similar approach. Upshur's principles could allow establishing a quarantine without having to impose it, in line with the suggestions of Brooks et al. in terms of mitigation strategies for quarantine's psychological effects: keeping it as short as possible, providing adequate supplies, paying special attention to communication and quality information, reinforcing the altruistic effects (Brooks et al. 2020). Everything looks simple, on paper and retrospectively. It is not, especially when dealing with such a complex topic. Upshur's principles are not so simple or straightforward to apply in a situation like the current one. First, and fundamental, drawing the line between individual rights and community interest is all but an easy task. One could argue that when an individual right (e.g. not having to bear the burden of a face mask) jeopardizes community interest (e.g. limiting the spread of an infectious disease) then it is fair to limit or suspend it. A straightforward libertarian would not accept such an argument, but should agree when considering "community interest" as an epiphenomenon resulting from the right to life and health of many other individuals. If this holds true for a trivial example as the "burden" of a face mask versus life and health, things become trickier when confronting life and death of unknown others with the (potentially total) income loss due to social distancing, so the (potentially total) loss of livelihood to provide for one's dear ones.

This is why, following the second principle, these measures need to be not only as mild as possible, but more properly as short as possible. Heavily uncertain scenarios demand flexibility, but people might be more willing to bear a stricter quarantine for a shorter period than a longer one, even if more relaxed (Brooks et al. 2020).

International solidarity risks to be hollowed to a bold claim with no substance, in a time in which Countries compete to be the first ones to secure themselves pre-emption rights on critical resources such as ventilators, face masks, drugs or vaccines (HHS 2020). Before embarking in such competitions, governments should seriously consider what kind of message they are giving, when on the one hand they ask their citizens to behave considerately and jointly, while on the other they act like the blindest utilitarian. This is something to take into account, when dealing with Upshur's third principle, reciprocity, on a broader scale. In Upshur's formulation, compensation is grounded on solidarity, and solidarity has nothing to deal with the aggressive international competition for scarce and critical resources mentioned above.

Upshur's fourth principle—transparency—needs an important integration in order to be applicable in contemporary democracies bigger than a tiny English village of the seventeenth century, and this integration is offered by the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights: "every limitation of personal freedoms", states the document, "should be discussed and applied by law, and not in an arbitrary manner". As Brooks et al. note, we lack studies comparing the effects of voluntary versus enforced quarantine (Brooks et al. 2020). But it is legitimate to hypothesize that when a quarantine is perceived as the result of a discussion, either direct or by representatives, and when enough information is provided to stress how this could help keeping safe other members of a community, particularly the vulnerable ones, people could be more inclined to compliance in self-quarantining and suffer less adverse psychological outcomes.

Noncompliance will always be an issue. There will always be people that, even if properly informed, involved and compensated, will never accept even mild temporary measures. In a healthy democracy this is impossible to avoid. From a normative standpoint, the Siracusa Principles offer some guidance in whether and how it is justifiable to impose limitations to personal freedoms in order to protect and promote public health: Article 12 (freedom of movement), Article 18 (freedom of thought, conscience and religion), Article 19 (right to hold opinions), Article 21 (right of peaceful assembly) and Article 22 (freedom of association) include "protection of public health" as a reason for imposing limitations (The American Association for the International Commission of Jurists 1985).

In fact, during the 2005 outbreak of extensively drug-resistant tuberculosis in KwaZulu-Natal, South Africa (Singh, Upshur, and Padayatchi 2007), the WHO embraced this approach, stating that "if a patient wilfully refuses treatment and, as a result, is a danger to the public, the serious threat posed by XDR-TB means that limiting that individual's human rights may be necessary to protect the wider public. Therefore, interference with freedom of movement when instituting quarantine or isolation for a communicable disease such as MDR-TB and XDR-TB may be necessary for the public good, and could be considered legitimate under international human rights law" (WHO 2007), specifying that this approach must be considered a last resort. And a very sad one, one might argue.

As a side note, it is important to stress the fact that containing this pandemic and mitigating the transmission rate is a necessity, not only "just" to save human lives, but also in order to avoid much more critical situations in which much worse ethical issues arise. Italy already faced a hard time in this sense: the Italian Society of Anaesthesia Analgesia Reanimation and Intensive Care Therapy has recently released a document providing guidance on how to prevent, or at least postpone, the collapse of the health care system by changing the allocation criteria for ICU care. The document recommends to carefully assess, among other factors, age, severity of illness, comorbidities and life expectancy before deciding to admit patients to ICUs, because "It is not a question of making purely value choices, but of reserving resources that may be very scarce first for those who are more likely to survive, and secondly for those who may have more years of life saved, with a view to maximisation of the benefits for as many people as possible" (Vergano et al.

2020). Other countries followed shortly after in having to face this intense deliberation process (Joebges and Biller-Andorno 2020).

Allocation of scarce resources is a painful nut to crack, as widely discussed in the vast body of literature dealing with the topic (Dolan et al. 2005), and it is just an example of the kind of difficult ethical choices our societies will have to face, should we fail containing the pandemic. During a pandemic outbreak quarantine measures do need to be put in place as timely and efficiently as possible, and this needs to be done also ethically.

Conclusion

Today's world is certainly more complicated than the rural English society of the 1600 s and the COVID-19 pandemic did not have its main outbreak in a village of 700 souls, but in Wuhan, a city of 11 million inhabitants, and that main outbreak has been followed by several others, scattered all around the world. It would be quite naive to infer that the same *actions* undertaken in Eyam could magically sort things out. Nevertheless, the history of Eyam and its voluntary quarantine, read in the light of Upshur's *principles,* can be an interesting ethical paradigm, useful in providing guidance on how to understand and deal with some aspects of the current situation.

First of all, we must bear in mind that the people living today are not radically different from the people of the fourteenth or seventeenth century, and that our instinctive responses to frightening and incomprehensible phenomena such as epidemics tend to converge. For this reason it is imperative to provide not only timely, but also politically coordinated and unambiguous information and actions in order to reduce the margins where social chaos tends to develop, of which the current attitudes of suspicion and xenophobia are the clear prodromes.

Secondly, both at local level (i.e. where the pandemic has active clusters) and at global level, it is necessary to employ only measures that are justified by an actual risk, that—considering in the first place their safety and efficacy—are as mild and short as possible, and that are as concerted as possible with all relevant stakeholders.

Above all, the international community must recognize that principle of reciprocity formalized by Upshur and also acknowledged by WHO **(WHO 2016, 30)**, providing continuous support—scientific, economic, logistical and human—to the communities affected by this pandemic. Recognizing the principle of reciprocity and writing policies based on it will not have the same symbolic power as bringing food to a place with romantic charm like the Mompesson well, but I do not see how this could reduce its validity.

A systematic reflection on these principles, before and while drafting measures meant to contain the pandemic, could help avoiding or at least mitigating that erosion of the social fabric and that radicalization of social conflicts that brought so much harm and that are again on the rise. We have a choice: to learn, reading the past in light of these reflections, or to constantly keep a watch, night and day, against the plague making us cruel as dogs one to another.

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3. The literature challenge

The explosion of scientific literature is not a new issue, nor it is specific to the COVID-19 pandemic. But the pandemic had a pedal-to-the-metal effect on this problem. Due to a series of reasons, ranging from funding policies to academic career evaluation systems, the academic community has become both master and slave of the 'publish or perish' regime. The question is: when so much literature is available at once, how do we identify what is relevant to our scope, and what is not? That is the focus of Chapter 3 (the only pre-pandemic work in this dissertation), in which I do not propose a solution, but a simple and efficient coping strategy.

Making Sense in the Flood. How to Cope with the Massive Flow of Digital Information in Medical Ethics.

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Abstract

Scientific publications have become the currency of Academia, hence the concept of 'publish or perish'. But there are consequences: the amount of existing literature and its proliferation rate have reached the point where keeping pace is just impossible. If this is true in general, it becomes a huge issue in interdisciplinary fields such as bioethics, where knowing the state of the art in more than one single discipline is a concrete necessity. If we accept the idea of building new science on an exhaustive comprehension of existing knowledge, a radical change is needed. Smart iterative search strategies, frequency analysis and text mining, techniques described in this paper, can't be a long run solution. But they might serve as a useful coping strategy.

Keywords

Publications' proliferation; Text mining; Search strategies; Information extraction; Topic tracking; Information science; Information systems management; Information technology; Content analysis; Data mining; Knowledge representation; Information management

Introduction

Scientific publications have played a central role in modern science since its very beginning: any result, no matter how good, has little to no value if it is not made public, available to peers to be analysed, discussed, questioned and maybe also used as a foundation or an instrument for further research. This is the original reason behind scientific publications. Born as a way to disseminate scientific news to a small audience of interested experts (Gotti 2006), over the last 350 years it has evolved into a complex and organized system, characterized by a detailed set of rules (theoretically) developed to guarantee the scientific quality of publications. The publication system, paralleled by bibliometrics, has improperly become a tool for evaluating careers, departments, research projects, and so on, often only from a quantitative point of view. In fact, the problems generated by purely quantitative approaches in research evaluation are recognised by the Leiden Manifesto for research metrics, one of the most influential documents aiming to outline a set of principles and best practices for scientometrics. Its first principle states that “quantitative evaluation should support qualitative, expert assessment”: support, not replace. (Hicks et al. 2015).

This shift of scope, from conveying knowledge to evaluating knowledge, has reshaped the way scientists write publications: the more, the better; the higher impact factor, the better. Lots of words have been spent on this topic, discussing and contesting many different aspects, from cross-field bibliometric comparisons (Bornmann et al. 2008) to the very idea of capturing “quality” with the amount and impact factor of publications (Lüscher 2018; Bornmann and Haunschild 2017; Callaway 2016). This paper has no intention to further deal with the political aspects of the issue; rather, the intention is to offer a set of instruments to manage the biggest consequence of the “publish or perish rule” resulting from the aforementioned shift of scope: the (over)proliferation of publications and the impossibility of keeping the pace with new literature.

It is not only theoretical speculation: even without considering the phenomenon of retracted literature (Brainard et al. 2018), and of predatory publishing (Bohannon 2013; Sorokowski et al. 2017), the existence of a relevant body of non-relevant literature (the pun is hard to avoid) is a fact that anyone engaging with, for instance, a systematic review can verify by her or himself.

In short, the problem can be outlined as follows: scientific publications are the currency of Academia, hence scientists publish a lot, and not always relevant things (where "a relevant thing" means adding at least a single brick to the building of science) (Binswanger 2014). But still, once a piece of literature is published, it becomes part of the corpus of knowledge on a certain topic, and cannot be just ignored a priori. This overproliferation has lead to the development of a set of "coping strategies" to try reducing the amount of time needed to keep the pace with growing amounts of literature. But rarely a coping strategy is a solution, and often, as I will discuss later, it implies some degree of bias.

The case of bioethics

If this process is true in general, it has a special impact on every interdisciplinary field, including bioethics (Eriksson and Helgesson 2017). Every researcher needs to be knowledgeable of a field in order to contribute to its growth, and bioethics has by necessity the need to include input from many different disciplines, considering more than one perspective on the same phenomenon. As an example, bioethically relevant literature on organ donation, a topic that has gathered vast interest over the last 65 years, comes from transplantation medicine, or from economics, or from philosophy, or from law, and so on. As a further example, consider for instance some simple queries on PubMed – see Table 1.

Query	Results
("2018/11/01"[PDAT] : "2018/11/10"[PDAT])	64857
(("2018/11/01"[PDAT] : "2018/11/10"[PDAT])) AND cancer[Title/Abstract]	6349
(("2018/11/01"[PDAT] : "2018/11/10"[PDAT])) AND breast neoplasms[MeSH Terms]	87

Table 1. PubMed queries. The first query displays the amount of new papers indexed in PubMed in a 10 days interval. The second displays the amount of new papers indexed in a 10 days interval mentioning "cancer" in title or abstract. The third displays the amount of new papers indexed in a 10 days interval using "breast neoplasms" as a MeSH indexing term.

Repeating the queries on different dates -but with the same ten days interval length- does not lead to big differences in numbers, meaning that every ten days there are around sixty thousand new indexed publications, six thousand about the broad topic "cancer" and about one hundred indexed with the specific MeSH term "breast neoplasms". MeSH, or "Medical Subject Heading", is a thesaurus created and maintained by the United States National Library of Medicine with the aim to reduce ambiguity in categorizing medical literature. It is organized in 16 categories, further divided into subcategories, resulting in a hierarchical tree structure.

If instead of looking to the last ten days we consider ten years, the scenario becomes really overwhelming. Figure 1 displays the number of publications per year found on Web of Science with the query TS=("end of life") AND PY=(2007-2017).

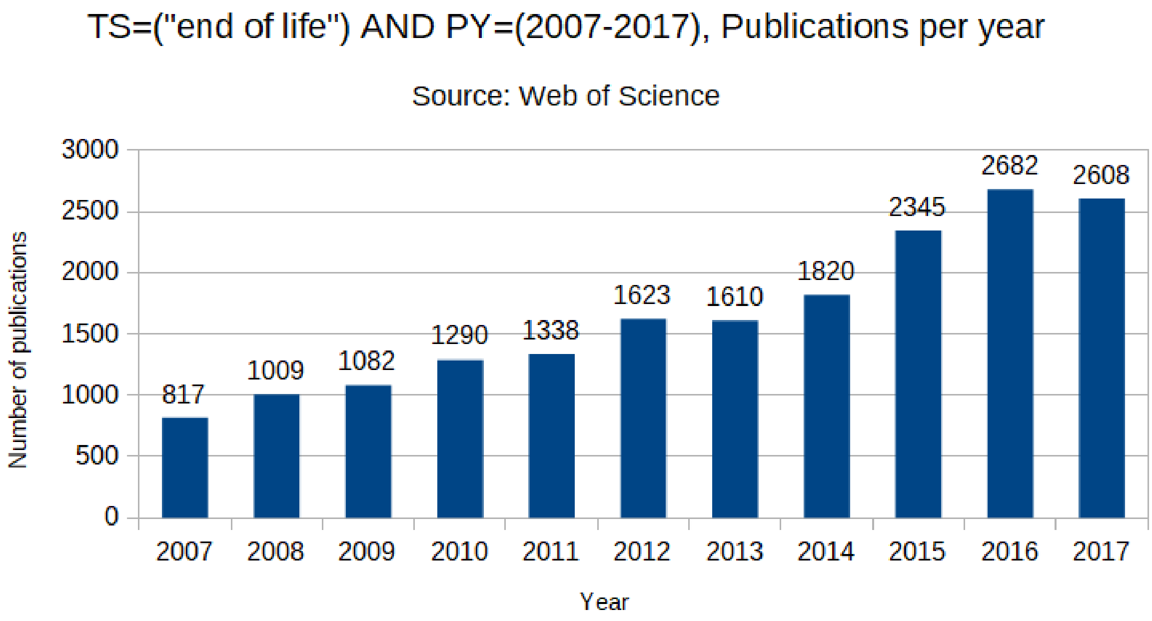

Figure 1, Number of publications per year indexed on Web of Science mentioning "end of life" as TS (topic subject) with PY(publication year) comprised between 2007 and 2017.

We are speaking of a corpus of 18224 papers that we can (arbitrarily) consider somehow "recent", growing at a steady pace. Considering other topics typically of interest for bioethicists, for instance "abortion" (n: 19264) or "informed consent" (n: 20862) the resulting amount of literature is more or less in the same order of magnitude.

The indexing issue

A precise indexing strategy, assigning unique descriptors to define the topic of a publication, is a functional tool to allow researchers to narrow down a query to include only what is really relevant for a specific research question. In this sense, with more than 25000 terms organized in a hierarchical structure, MeSH indexing is a fundamental instrument to retrieve medical literature discussing very specific topics (Lowe and Barnett

1994). Its effectiveness, tested, developed and consolidated since 1960, is due to four factors: it is comprehensive, unambiguous, clear and widely accepted.

Unfortunately there is no such a thing as a comprehensive, unambiguous, clear and widely accepted indexing system for bioethical literature. For example, in a systematic review assessing the different methodologies applied in empirical ethics, the authors were able to identify four main methodological categories, which is completely understandable and acceptable in a pluralistic and interdisciplinary field. The surprising (and disorienting) finding is that each one of these four categories includes a plethora of synonymic or semi-synonymic methodologies: 4 in 'Dialogical Processes', 3 in 'Combination of Dialogical and Consultative Processes', 22 in 'Consultative Processes' and 7 in 'Neither Clearly Dialogical Nor Consultative' (Davies, Ives, and Dunn 2015).

Ambiguity and synonymity are two sides of the same coin, depending on the plastic nature of language and on its not always rigorous use. The notion of "justice" is a good example in this sense. Beuchamp and Childress, for instance, identified at least six families of theories, all of them using the same term, "justice", and all of them grounded in the same Aristotelian formal principle ("equals must be treated equally") but resulting in very different material principles, ranging from utilitarian frameworks (justice as maximization of social utility) to Madison Powers and Ruth Faden's wellbeing theory (justice as guaranteeing to every individual the functioning of the six core dimensions of well-being) (Beauchamp and Childress 2013, 253).

The problem becomes even more relevant in interdisciplinary research. The word "ontology", for instance, is used by both philosophers and computer scientists, but while philosophers understand it as the metaphysical study of Being in itself, for computer scientists an ontology is "an explicit specification of a conceptualization", or better, "a specification of a representational vocabulary for a shared domain of discourse – definitions of classes, relations, functions and other objects" (Gruber 1993; Breitman, Casanova, and Truszkowski 2007). When philosophers meet computer scientists and discuss ontologies, preliminary terminological clarifications are of paramount importance.

In a context in which the same word can have different meanings, conceptual clarification is of paramount importance, and better indexing can be a solution. Developing a MeSH-like indexing system for bioethics that aims to categorize topics and reduce ambiguity would surely be an indispensable and daunting enterprise that the scholarly community should seriously consider. Nevertheless, the whole effort would likely take several years before consensus and implementation, years that will likely see a continuous growth in uncategorised literature, or better, in literature categorised with the current ambiguous systems. A "BeSH tree" would be an instrument for the future, but not a solution for the present.

Selection bias

The issue of bias in information retrieval is well known and well debated in the literature, and several authors proposed taxonomies for different kinds of bias that can impact research (Booth, Sutton, and Papaioannou 2016, 19).

Selection bias is the kind of systematic error that can have the most detrimental impact on a literature review. It is conventionally understood as a form of bias in which "a reviewer selects primary research studies that support his/her prior beliefs" (Booth, Sutton, and Papaioannou 2016, 19). In a broader sense, selection bias implies a purposeful selection of the literature included in a study, either a posteriori (as in the aforementioned definition) or even a priori, selecting the sources of information to be used.

Numbers indicate that it is simply impossible to keep pace and read everything on a specific topic, even a quite narrow one; moreover, the lack of an indexing system means that there is no tool to filter safely what is really relevant from what is not. So we face a question: assuming that we consider it ethical to have both a granular understanding and an overall view of the field we want to work in, how can we reduce the amount of non relevant literature to deal with, without wasting too much time and losing relevant information? Three pseudo-solutions are usually employed, and all of them are biased to some degree:

"The newer, the better". Even if somehow valid in STEM (Science, Technology, Engineering and Mathematics), this is an approach which is not viable in bioethics. There is no need to embrace a conservative standpoint to recognize a simple fact: plenty of fundamental bioethical literature is "old", or at least older than ten years. The WMA Declaration of Sydney (1968), the Harvard Report (1968), and the President Commission's report on the Protection of Human Subjects in Biomedical and Behavioral Research (1981) are three clear examples;

"The most cited, the better" is a flawed approach in principle: it starts a positive feedback loop that marginalizes articles that might be relevant, but for some reason didn't receive an initial burst of citations at their publication ("reputation echo chamber") (L. Kim, West, and Stovel 2017);

"Follow a specific tradition/approach" is flawed in principle as well: the consequence is the loss of a global perspective on the field ("heritage echo chamber").

Smart iterative search strategies

These three distinct but closely related problems (publication proliferation, poor indexing and selection bias) have a possible common solution in the application of Smart Iterative Search Strategies (SISS). The overarching idea is quite simple: text mining software can analyse more data than a person; thus, if properly set up and "fed", it can reduce selection bias and has the ability to cope with poor indexing.

Interactive query expansion and interactive query formulation have been already discussed in the literature from a theoretical point of view, and have been successfully applied in different contexts (Y.-H. Liu and Wacholder 2017; Haunschild, Bornmann, and Marx 2016): according to Efthimiadis, the expansion of an initial query with related terms (hierarchically, in the context of MeSH-like trees, or by similarity using a thesaurus) leads to high user satisfaction in information retrieval (Efthimiadis 2000). Wacholder, in a more recent review, described the cognitive process of Iterative query formulation, intended as an information retrieval activity in which "the information seeker has input from the results of previous searches (from the same session). Basic QF is at the core of iterative QF but the process is modulated by the additional entities and increased complexity of the flow of information" (Wacholder 2011).

In Wacholder's description, iterative QF and basic QF are presented as activities heavily depending on the user, who is responsible of crafting the initial search strategy, revising the results, and eventually deciding how to modify the initial query. SISS is a set of techniques that aims to offer a practical implementation tool to automatize some of these passages. In short, it is a way to analyse large amounts of text in order to refine the initial query, including relevant keywords and yielding to more relevant and comprehensive results. Moreover, being based on the application of an algorithm, it is *per se* less prone to the selection bias that a user could introduce in the process of selecting relevant terms for the expansion of the query.

Text mining (and computational linguistics in general) have entered the spotlight, being widely used for security purposes, biomedical applications, understanding markets or tracking political discourse (Gupta and Lehal 2009), and there is also increasing consensus regarding their application as instruments to speed up systematic reviews (or, at least, to keep the pace with published literature) (Ananiadou et al. 2009; Thomas, McNaught, and Ananiadou 2011; O'Mara-Eves et al. 2015). Moreover, thanks to open source online based instruments such as Voyant Tools (Voyant Tools 2018), these techniques have become easily and widely available. Voyant Tools, originally conceived to "enhance reading through lightweight text analytics such as word frequency lists, frequency distribution plots" (Klein, Eisenstein, and Sun 2015) is the oldest and most widely used tool to support interactive exploration of large linguistic corpora.

Nevertheless, since computational linguistics is a field of its own with a growing body of literature and techniques of increasing complexity, approaching the issue from the point of view of a bioethicist with little to no formal training in computer science could sound daunting. But it is not. Some of these techniques are rather easy to apply to one's everyday research workflow.

Let's assume, as a case study, that we are interested in the ethical aspects of human genetic enhancement. A quick search for TITLE-ABS-KEY(human AND enhancement AND ("gene" OR "genes" or genet*) AND ethic*) on Scopus yields a considerable but not enormous number of results (n: 688), providing a good test case. Scopus (and many other databases) allows us to order chronologically the results and export their abstracts, which can then be fed into Voyant Tools (see Table 2).

#	Word	Count
1	genetic	2644
2	human	1901
3	enhancement	1790
4	ethics	1096
5	gene	986
6	genetics	867
7	therapy	779
8	research	730
9	medical	718
10	inward	688
11	social	673
12	health	622
13	ethical	608
14	humans	592
15	engineering	538
16	reproduction	532
17	moral	465
18	approach	423
19	biomedical	410
20	technology	339
21	life	311

22	public	296
23	cell	282
24	bioethics	281
25	risk	279
26	germ	278
27	care	272
28	rights	248
29	policy	239
30	reproductive	238

Table 2. Voyant Tool Frequency Analysis, first 30 results. The first column represents the word's frequency ranking in the corpus, the second represents the word, the third represents the number of occurrences.

It is interesting, at this point, to examine the relative frequencies and the sparkline graph trends of the words in the corpus, looking for other concepts emerging under the surface of the initial query and for how often they have been mentioned in different moments of time. After adding some standard stopwords (s2.0, eid, https, http, md5, partnerid, record.uri, www.scopus.com, doi, article, journal, keyword, index, author, abstract) to get rid of some noise, we know, without any prior knowledge of the field, that the question is considered "medical" or at least related to health, strictly connected with social issues, and related to reproduction.

A final detail: as is well known in the literature, there is a stark contrast between the concepts of enhancement and therapy, often presented and discussed as opposites, embedding different moral values and implying different moral duties (The President's Council on Bioethics 2003). Voyant Tools can show how the frequency of a word varies in different segments of the document, and it allows us to use wildcards (e.g: enhance* or therap*). Confronting the variation in frequency of these two clusters of words over time we can clearly see that between the late '90s and the early 2000s (segment 2) the concept of therapy has become less discussed in this field (see Figure 2).

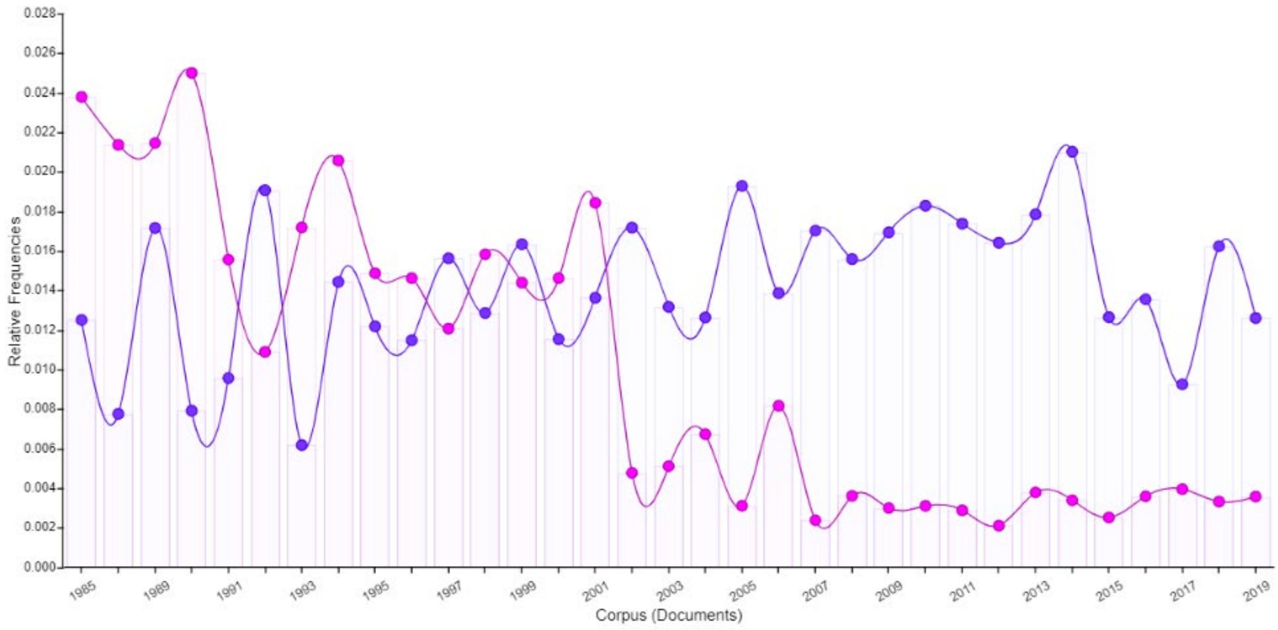

Figure 2. "Therapy" (purple line) vs. "Enhancement" (blue line) in Genetic Enhancement literature. Results from the Scopus query have been downloaded as text and divided by year of publication. Each segment is one year. Each word has been lemmatized (i.e: therap and enhance*) in order to show the relative frequency of the semantic groups in the segments.*

This comes as no surprise to anyone who is familiar with the content of the report cited above. But it is of great value to see the change in the debate without having to read the texts, from a quantitative perspective. In the same way, it is possible to confront the trends of any word, or cluster of words.

At this point, after understanding the general trends in the field and identifying an interesting question, the process can be iterated, refining the query, exporting a (smaller) number of abstracts and exploring them with the same text mining techniques.

Full text frequency analysis and text mining

If adopting frequency analysis techniques in the preliminary phase of the development of a new research project or while approaching a new topic is helpful, it can be really useful also in a later phase when the relevant literature for a specific topic or project is already identified and available in full text, and it has to be assessed. In this case, the traditional approaches are two, and again both are biased to some degree:

"First in, first out and read everything": feasible, but the risk is ending up with a massive amount of disconnected notes, precise on the single paper but lacking an overall picture of the concepts discussed, and of their evolution over time;

"Read the abstract first, then read the paper only if the abstract seems relevant": there is a consistent risk to arbitrarily miss relevant studies just because the abstract is not fancy enough.

But what if we had the possibility of having both a general and a granular understanding of the literature in our corpus, being able to see at the same time the big overarching trends and small but fundamental details? If for the latter it is (still) indispensable to allocate some quality time to the pleasure of reading, for the former there is a solution provided by the application of frequency analysis techniques to full text articles.

An interesting case study in this sense is offered by the literature on organ donation, which is a broad topic, widely discussed, with a lot of literature, coming from different fields, and ranging from theoretical positions to empirical studies. A recent request for a report on the influence of consent models, donor registries and family decision on organ donation rates, realized for the Swiss Federal Office of Public Health (Christen, Baumann, and Spitale 2018) has been an excellent opportunity to test the system. After defining a precise and comprehensive search strategy by means of SISS, we downloaded all the obtained papers and fed them into MaxQDA (Woolf and Silver 2017), a program designed for qualitative research and coding that recently introduced some easy and useful functions for frequency analysis.

The first pass was plain frequency analysis, that can be performed on single words or on couples/triplets of words (see Table 3). This type of analisys can help us look for emergent concepts and to define further exploration strategies. For instance, in this case we had a first intuition about opt-out systems being much more discussed (caveat: discussed does not mean favoured!) in comparison with opt-in.

Word combination	Frequency #	%	Present in documents, #	%
organ donation	1648	1.66	67	98.53
organ donor	438	0.44	49	72.06
presume consent	412	0.42	45	66.18
opt-out system	377	0.38	50	73.53
opt out	297	0.3	45	66.18
donation rate	279	0.28	41	60.29
http www	274	0.28	49	72.06
their organ	230	0.23	42	61.76
potential donor	223	0.22	43	63.24
does not	190	0.19	45	66.18

Table 3. MaxQDA Frequency Analysis, couples of words, first 10 results.

Dictionary based frequency analysis is an evolution of frequency analysis: we might know, from familiarity with the field or from a preliminary frequency analysis, that some concepts can be expressed in more than one way (namely: “opt in” or “opt-in” or “opting in”). Dictionary based frequency analysis is the solution for this issue: defining a list of synonyms or semi-synonyms allows us to aggregate all the possible variations of a concept, and count them together. It is important to keep in mind that the compilation of such a list is a delicate task and requires some degree of familiarity with the topic and with the lexicon used to discuss it. For example, failing to include the world “boyfriend” among the synonyms and semi-synonyms of “partner” will introduce another source of bias.

The results, i.e., the overall frequency of the words of a dictionary, can be shown aggregated for an entire corpus or for a single paper. If the first feature is of great utility in cases like opt in vs opt out, the latter is extremely useful (especially if combined with basic filtering and ordering tools provided by Excel or similar software) to identify at a glance the literature that is likely to be more important in order to understand a specific problem in a given corpus.

Table 4 is an example of the results obtainable with dictionary-based frequency analysis. First a query on shared decision making in young hemato-oncologic patients was defined by means of SISS, then all the literature was retrieved, then a dictionary was built for each of the relevant categories (autonomy, responsibility, patient, physician, nurse, family), and finally they were used for the frequency analysis. From the data we know, for instance, that the concept of responsibility is more debated than autonomy, and that the role of physicians is less debated that the role of families, but more than the role of nurses.

Name	autonomy	responsibility	patient	physician	nurse	family
TOTAL	175	450	14964	5768	2246	6084
Sainio, Lauri 2003	2	1	238	58	86	39
Tang, Lee 2004	7	1	314	74	17	113
El Turabi, Abel et al. 2013	1	1	321	10	2	17
Shepherd, Woodgate 2011	0	6	14	15	53	186
Knopf, Hornung et al. 2008	3	11	124	88	7	17
Langbecker, Ekberg et al. 2016	0	7	115	29	134	25
Ishibashi, Ueda et al. 2010	1	1	82	30	49	146
Cohen, Botti 2015	1	1	299	25	54	33
Trarieux-Signol, Bordessoule et al. 2018	12	1	291	57	0	91
Carey, Anderson et al. 2012	0	3	130	35	4	25

Table 4. MaxQDA frequency analysis, dictionary based, results per paper, first 10 results. The first column identifies the paper. Columns 2-7 display the absolute frequency of words contained in each one of the 6 dictionaries.

As a last treat, it is also possible to further narrow down frequency analysis using autocoding, a feature of MaxQDA originally developed to speed up qualitative research. In short, the autocoding feature divides the text into sentences, looks for the presence of a word contained in the dictionary in each sentence, and if one of these words is found, tags that sentence with the name of the category that the word belongs to. As a practical example, given a dictionary like "hair = (hair, eyebrow, sideburn, eyelash, moustache, beard, wig)" and a sentence like "This morning I forgot to shave my beard", this sentence would be autocoded as "hair". This way it is possible to build a set of "subcorpuses" containing all the sentences that contain a specifc set of keywords, like all the sentences concerning "autonomy" or all the ones on "patient", or even all the ones mentioning both. Then it is possible to explore these subcorpuses with the same techniques discussed above, understanding for instance what are the most common concepts associated with "patient autonomy". Finally, after "mapping" the overarching themes and building a general understanding of the literature, it is time to "go granular" and proceed with a manual content assessment by reading the papers.

Discussion

The (over)proliferation of scientific literature in general is a problem too big not to be acknowledged, and it is hard to overestimate its impact on an interdisciplinary field such as bioethics, where gathering and understanding information coming from different disciplines is fundamental. It is a fact: if we want to ground future science on existing knowledge, we have two possibilities. The first is to dramatically reduce the amount of published literature, decoupling the publisher's revenues from the number of papers published and thus removing incentives to publish "noise" (Aguzzi 2019) and finding better ways than sheer bibliometric indicators to evaluate academic careers (Binswanger 2014). The second, as already discussed, is to develop and systematically employ comprehensive, unambiguous, clear and widely accepted indexing systems, modelled on MeSH – like taxonomies.

Both are clearly long-term, hard to accomplish solutions that need to be discussed and pursued by the scholarly community. Meanwhile, the methodology here described as "Smart Iterative Search Strategies" (SSIS) can be a practical way to "cope with the flood", to define more refined search strategies, explore search results, get the general sense of the literature captured by a query, and ultimately reduce the number of papers to be downloaded and read without incurring one of the three kinds of selection bias described above.

In this context, full text frequency analysis and text mining are complementary techniques, relatively easy and fast to perform, allowing one to build a preliminary map of concepts and topics discussed in a given corpus that can be used to build a general perspective, a starting point for manual assessment of the content. Nevertheless, there is a caveat: it is important to remember that from the point of view of frequency analysis, assuming that we are interested in concepts such as "nose" and "nice", the sentences "my nose is nice" and "my nose is not nice" are identical: their meaning is opposite, but they both mention the same concepts. Results obtained with frequency analysis are not final results, but powerful hints about what is going on in large bodies of text.

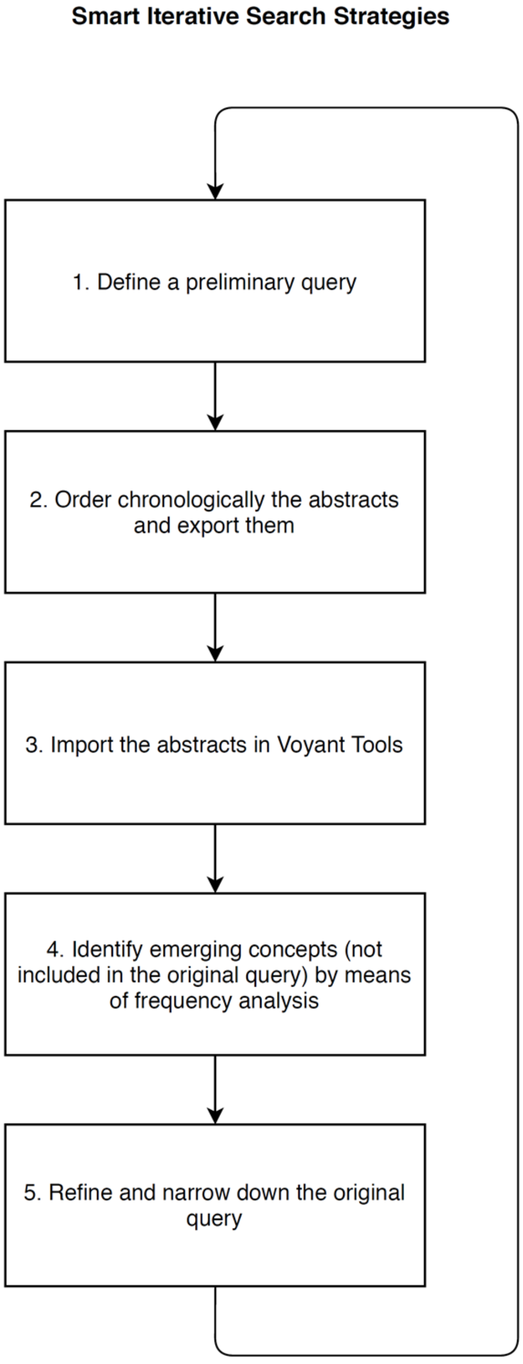

Figure 3. The five steps of Smart Iterative Search Strategies, from the definition of a preliminary query to its refining through frequency analisys.

Conclusion

Are we able to really know and understand all the literature on a certain topic, keeping pace with new publications? Unless the topic is really narrow, the answer is a clear "no". A situation less than ideal, risking to transform science into an uncoordinated and chaotic effort.

The issue of literature overproliferation could lead the scientific enterprise *per se* to a critical spot, a "no turning back point" where there is a dramatic loss of meaning. An instrument originally introduced as a way to convey knowledge has grown too fast in comparison to our ability to get the meaning out of it, becoming a source of noise and a huge time devourer. On the one hand, we definitely need to find a way to limit the growth of non-significant literature, or of literature that has purposes other than conveying knowledge. On the other, we need better strategies to navigate large amounts of text in a fast, efficient and non-biased way.

Smart iterative search strategies, full text frequency analysis and text mining are not a solution, in contrast with developing and implementing a MeSH-like indexing system for bioethical literature, or finding a structural way to "change the currency of Academia". Nevertheless, Smart Iterative Search Strategies, Full Text Frequency Analysis and Text mining, if properly employed, can be a good working strategy to cope with this massive flow of information.

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4. Emerging ethical issues

The strategy detailed in Chapter 3 came rather handy during the COVID-19 pandemic: due to the urgency of the issue – and arguably, due to rapidly changing research funding schemes – the amount of literature on the ethical aspects of epidemics and pandemic management rampaged, making it more and more difficult to keep current with the state of the field. Based on the approach described in Chapter 3 (smart iterative search strategies) we developed a software able to search, download, and map the content of large numbers of PubMed records using NLP (natural language processing). In the study presented in Chapter 4 we applied this software to identify and understand what the scholarly community describes as 'emerging ethical issues' in the context of the COVID-19 pandemic.

Addressing Volatile Ethical Issues of Covid-19 with the Core Five Enduring Values List for Health Care Professionals

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Summary

From an ethical perspective, the pandemic is like a prism: it helps us see the spectrum of issues clearly and distinctly. In our contribution we shall outline what we consider top ethics concerns, grouped around five moral and societal core values: autonomy, privacy, equity, proportionality and trust. We then proceed to probe these concerns a bit further

with some examples around vaccination of health care professionals, contact tracing, global access to vaccines, lockdowns, and crisis communication. We are quite aware that the dynamic, cross-sectoral, multilevel impact of both the pandemic and the measures taken to contain it is too complex to be captured by a simple short list of ethical issues. This is a huge challenge for healthcare leaders and healthcare professionals. To keep a clear and current overview of this moving target, we propose a value-based checklist, centered around five core moral values which are unlikely to change over time, that will allow healthcare leaders to systematically analyze ethical issues arising in their institutions. Each section of the checklist (centered around one of the core values) includes a dynamic presentation of emerging topics (in the form of a word cloud or any other suitable format) that can and will change, generated with a natural language processing (NLP) approach, using an open-source topic tracking algorithm as a means of tackling the exploding volume of literature on bioethics and COVID-19, allowing for quick overview of thematic priorities.

The pandemics as a prism for ethical issues

For over two years the COVID pandemic has taken center stage, pretty much anywhere around the world. Not only has it caused death and suffering, but it has also absorbed our energy and attention. Other global issues such as climate change or the privatization of space have gone almost unnoticed. For ethics, the pandemic is like a prism: it helps us see the spectrum of issues clearly and distinctly. In the following we outline what we consider top ethics issues, grouped around five moral and societal core values, and probe them a bit further with some examples.

The pandemic affects not only our physical but also our mental and social wellbeing. It affects individuals, groups and the global community. It has triggered the rapid development and accelerated the deployment of new technologies, many of which involve digital and AI components such as tracing apps and triaging algorithms. We are quite aware that the dynamic, cross-sectoral, multilevel impact of both the pandemic and the measures taken to contain it is too complex to be captured by a simple short list of ethical issues. Our contribution can only be a teaser for a deeper dive into the plethora of Covid-19-related moral questions.

This is why we end this paper with a value-based checklist that allows healthcare leaders to systematically analyze ethical issues arising in their institutions. In addition, we suggest an open-source digital topic tracker as a means of tackling the exploding volume of literature in bioethics, allowing for quick overview of thematic priorities and gaps in the existing literature.

The Big Five: ethical issues of COVID-19

1. The role of autonomy, individual rights and freedom in a pandemic

Citizens around the globe have been subjected to serious restrictions of their liberties: Quarantine requirements, closed borders and curfews have limited our ability to move freely; events and gatherings including political demonstrations have been banned; we have not been able to visit family members even when they were seriously sick or dying; we have been required to reveal personal information, for instance when going to a restaurant, to enable contact tracing; we have been required to wear masks, many have not been able to attend schools or go to work (Secretary General of the Council of Europe 2020b; 2020a) Vaccine mandates have been discussed, and in some countries applied (Druml and Czech 2022); and nudging strategies like limiting access to public spaces or facilities to vaccinated individuals have been enforced, not without controversy (Spitale, Biller-Andorno, and Germani 2022a).

All of this has happened, of course, for good reason. Still, there is some uneasiness around the sudden – albeit temporary – loss of personal liberties that had been taken for granted by citizens in many countries. Careful legitimation of restrictions as subsidiary to individual responsibility and restoration of civil liberties as soon as possible will be important from an ethical and human rights perspective (Studdert and Hall 2020; Flood et al. 2020).

A current example of weighing individual freedom and autonomous choice against public health concerns vaccination against Covid-19. Whereas the speed with which vaccines have been developed surpassed most people’s expectations, there is surprisingly widespread hesitancy to get vaccinated (Spitale, Biller-Andorno, and Germani 2022a; Barello et al. 2020; Peretti-Watel et al. 2020; Dror et al. 2020). For some, this hesitancy may be rooted in a principle anti-vaxx stance, others may be skeptical because of the great speed with which vaccines were tested and approved (Murphy et al. 2021; Puri et al. 2020; Wouters et al. 2021). Whereas an argument can already be made for every citizen to carry a responsibility to contribute to herd immunity, matters get even more acute in the case of health care workers. Interestingly, it is this group who is not only particularly exposed but also at risk of spreading the disease among vulnerable patients that seems to be in large parts unwilling to receive the vaccine (Kirzinger et al. 2021). There is a spectrum of possible responses from acceptance of refusals to nudging to indirect pressure (e.g. vaccination requirement for certain activities) to compulsory vaccinations. Finding the least invasive measure that is still effective enough to protect the health of patients will be a task that needs to be tackled in the context of national regulations, considering a range of empirical factors, including the urgency of the intervention, the availability of alternatives, and likely reactions.

2. Privacy vs. efficient and effective pandemic management

A second set of ethical issues revolves around privacy, another core value in liberal democracies. The availability of data is key to fight a pandemic. Very different kinds of data can be helpful to understand the impact of the pandemic and the measures taken to contain it on population groups (Gasser et al. 2020) . Among those data are, for instance, proximity and contact tracing, flow modelling and quarantine compliance. Proximity and contact tracing is a way of trying to follow and break infection chains. Tracing apps were developed in many countries, requiring difficult trade-offs between effectiveness and data protection and thorough ponderation on potential risks (repurposing of the tracing systems or of the data after the pandemic, data access, possibilities of re-identification using collateral datasets, security vulnerabilities, and (im)possibility to withdraw consent and erase personal data) (Ahmed et al. 2020; Braithwaite et al. 2020). But again, voluntary uptake of the apps was not overwhelming in many countries (Walrave, Waeterloos, and Ponnet 2020; Munzert et al. 2021; Jonker et al. 2020). And indeed, the voluntary use of a tracking device presupposes significant trust not only in the technology but in the government and other players who may access the data. This trust might be put at risk if choice architecture is used to make people use such tools (e.g. through opt-out schemes) against their conviction.

Ethical questions such as "Should police enter a building against residents' will if they suspect a party with more than the permitted number of participants?" can also emerge in low-tech settings. However, digitalization has greatly enhanced the potential for effective surveillance, for instance using IoT devices for live tracking, employing personal movement data to model potential disease activity, tasking AI applications with detection of COVID-19 from chest imaging (Ting et al. 2020; Budd et al. 2020), or even using robotic dogs to enforce social distancing (Nalewicki 2020). In analogy to restriction of autonomy and individual freedom, privacy intrusions need to be very carefully justified, transparently communicated, secured against abuse and abolished as soon as no longer required. Finally, as emerged from a recent study on no-green-pass groups, a clear communication on the scope, duration, and limitation of measures that compress the space of individual privacy could be a crucial factor to improve the uptake of these measures (Spitale, Biller-Andorno, and Germani 2022a).

3. Equity, fairness and solidarity under conditions of resource scarcity

From an ethical point of view, it seems fairly straightforward that ending a pandemic requires global cooperation and that scarce resources should be allocated according to need.

Yet equitable distribution of goods such as intensive care beds or vaccines has proven a highly complex issue (Holzer et al. 2021). Over the past year, numerous guidelines have been developed that define allocation criteria and procedural rules (Jöbges et al. 2020). Key considerations that have emerged relate to maximizing utility, non-discrimination, fairness and protection of vulnerable groups.

Recent struggles regarding the distribution of still scarce vaccines show that implementation of seemingly simple rules and criteria is not easy in real life. Although an international mechanism for the global distribution of vaccines has been established (CEPI et al. 2020; COVAX 2020), governments are securing supplies through bilateral agreements with pharmaceutical companies. The stock of some countries by far exceeding their need, whereas others have not even been able to start vaccination programs due to a lack of vaccines (Wouters et al. 2021; CEPI 2020; Khamsi 2020). Whereas moral consensus can easily be reached that hoarding is not defensible in the face of resource scarcity, there is a lively ongoing debate between nationalist and cosmopolitan views. A further level of complexity is added by the fact that not all vaccines are equally safe, effective and easy to transport and store. The debate is fueled by the expectation that vaccinated individuals or societies will have restrictions lifted and go back to normal more quickly than those not protected by a vaccine. Given the tremendous societal and economic impact of measures such as closed shops and travel restrictions, the speed of vaccination carries is highly significant for many countries.

4. Proportionality of measures: legitimation and procedures

Governments struggle with the giant task of how to maneuver best through the crisis. There are different perspectives on how much of a top-down approach is needed, how much controversy can be afforded and to what extent citizens should be involved in evaluating and prioritizing options. It has become clear, however, that building resilience involves a multilevel network of interconnected drivers and health, social, economic and environmental systems and – at least in democratic societies – needs to rely on participation, communication, coordination, learning and polycentricity as governance principles (Antulov-Fantulin et al. 2021).

How proportionality is to be established in concrete cases – e.g. such as shutting down hotels based on a certain incidence level – is a question that currently intensely debated among legal scholars. Although the issue is disputed (Prati and Mancini 2021), there are voices from within the academic community in different countries who question the proportionality of protracted lockdowns, which might eventually cause, so the argument, comparable or even more damage to populations than the pandemic would have had (Luo et al. 2020; Salari et al. 2020; Vindegaard and Benros 2020). How proportionality should be established, by whom, according to which criteria and procedure is currently a field of contention. In bioethics, there is a clear distinction between the descriptive and normative level, i.e., it is not given that 'what people believe' is per se 'the right thing to do'. Nevertheless, empirical data collected through citizen science approaches can greatly contribute to informing this debate with contextual information, e.g., on acceptability thresholds.

5. Trust and trustworthiness

The pandemic and its management have put high demands on public trust. Particularly in the early phase, little evidence was available on crucial matters such as infection rate, available treatment, effective preventive measures, case fatality rate or risk factors. The paucity of high-quality evidence contrasted with the abundance of mis- and disinformation, especially on social media (Gallotti et al. 2020; WHO 2020b; 2020d). At the same time, the pandemic and subsequent public health measures have severely affected the lives of most people around the globe. Crisis communication therefore played a key role in maintaining trust and enhancing the likelihood of compliance with hygiene and other rules.

Communication, however, has tended to be quite directive and unilateral. Whereas this may have been appropriate in the early phase of the pandemic, a more bidirectional approach is needed in the longer run. Not only do citizens need to know what health authorities want them to do – health authorities also need to know how citizens perceive the situation, how they react emotionally, how they are likely going to behave and what stance they take on moral questions such as the allocation of scarce vaccines. Such a nuanced, comprehensive understanding is necessary to tailor information and policy responses. Again, digitalization provides excellent opportunities to build interactive platforms that allow for real-time analyses (Spitale et al. 2021b).

Trust, however, is only a good if it is justified. Authorities should therefore not only try to obtain citizens' trust but to also deserve it as trustworthy institutions doing their best at correctly informing, devising appropriate measures that take into account what parts of the population will be affected and how, and ensuring conflicts of interest do not get in the way of the overall aim of reducing the harm caused by the pandemic – either directly, through its health impact, or indirectly, through measures taken to contain it. An important challenge for authorities relates to the question of how to deal with radical dissenters who might influence others with unfounded conspiracy theories and open opposition to public health measures. Although certain measures might be justified to maintain public order, oppressing diversity of opinion through overreaching censorship might encourage societal polarization. Prudent judgement will be in place to respect freedom of expression without compromising social stability.

A Covid-19 value-based ethics checklist

Although we are confident that we have captured key values and moral tensions exemplified by concrete examples we do see some added value in systematically looking at the published international literature (in English) to get a sense of where priorities have emerged, but also to investigate which topics may have received less attention. Our goal is to complement the theoretical reflection based on which we developed the Big Five with a checklist of concrete issues in which the Big Five play a pivotal role. As healthcare leaders need to keep abreast of their COVID-19 management, and issues have become so manifold, it is important to keep an overview. Therefore, we propose an up-to-date analysis of current issues structured around the Big Five, generated through an innovative digital tool.

This approach has an important added value: this analysis can be rapidly and dynamically updated with a re-run and re-analysis of the same queries, a crucial feature when dealing with fast-paced situations subject to rapid evolution – as proven by the sheer number of papers captured by our queries.

The TopicTracker – navigating through the flood

For this purpose, we have developed a digital tool to search, download and explore PubMed entries. The TopicTracker is written in Python and structured in a collection of three Jupyter notebooks in order to provide together the code and its explanation. The first notebook allows to build PubMed queries, download entries, parse them, and save the results. The output of the first notebook can be explored with the second and third notebooks of this collection. The second notebook allows to perform simple NLP analysis on the trends of entities (keywords, MeSH terms, authors, journals, lemmas in title/abstract, amount of COI statements, lemma trends in COI statements). The third notebook allows fully interactive exploration of the datasets preprocessed with the second notebook. The whole package is available through the Zenodo repository under a Creative Commons Attribution 4.0 International license (Spitale and Biller-Andorno 2021a).

Strategy

To determine the core areas of discussion about the interplay between the Big Five and the COVID-19 pandemic, we ran a set of five queries (detailed in Appendix 1) in the TopicTracker. Each query collects articles regarding COVID-19 and one of the Big Five, published between 2019 and March 2022. Medline files resulting from the queries and TopicTracker logs are available upon request for further research.

In order to develop a dynamic checklist, we focused our analysis on keywords and MeSH terms. To correct for the different number of publications per year (especially keeping in mind that the query has been run in March 2022) we normalized all the frequencies dividing the count per year by the number of articles published in the same year captured by the query. Keywords and MeSH terms cannot be duplicated, so they can be understood as percentages (100% = every article uses that keyword/MeSH term).

Results

Although we consider all the Big Five of equal importance, some topics appear to be more discussed than others, suggesting that in some specific areas further research is needed, especially on proportionality and on privacy. Results are reported in Table 1. Detailed output (normalized dataframes of keywords and MeSH terms, word clouds and plots of the top 5 entities in each dataframe) are available upon request for further analysis.

Query	Papers
The role of autonomy, rights and freedom in a pandemic	2215
Privacy vs. efficient and effective pandemic management	895
Equity, fairness and solidarity under conditions of resource scarcity	2659
Proportionality of measures: legitimation and procedures	55
Trust and trustworthiness	2311

Table 1. Detailed results of the five 'big five' queries

The role of autonomy, rights and freedom in a pandemic

Scholarly discourse on autonomy, rights and freedom focuses mostly on recognizing and incorporating human rights when developing or deploying public health measures, namely quarantine and lockdown. Other areas in which autonomy plays a central role appear to be telemedicine, surveillance systems, and vaccines. Normalized MesH terms provide good methodological hints, suggesting that empirical work in this area is primarily conducted with surveys, questionnaires, and qualitative approaches.

Figure 1. Word cloud of the top 50 keywords in the 1st query

Privacy vs. efficient and effective pandemic management

Privacy plays a central role and is a key concern in a number of practices that emerged during the pandemic: contact tracing, telemedicine, digital health, surveillance, mHealth, and telepsychiatry. Articles discussing about privacy in the pandemic context engage with specific technologies, including blockchain, artificial intelligence, machine learning / deep learning, and big data. The pivotal role of mobile / smartphone-based technologies when dealing with privacy issues is confirmed by the MeSH terms. The amount of papers dealing with privacy is significantly lower when compared with other topics, suggesting that further research in this area is needed.

Figure 2. Word cloud of the top 50 keywords in the 2nd query

Equity, fairness and solidarity under conditions of resource scarcity

Research on equity and COVID-19 revolves mostly around resource allocation and triaging. Nevertheless, equity, fairness and solidarity are considered also in scholarly work targeting health disparities, social determinants of health, racism, and social justice. Also the keywords 'mental health' and 'mortality' are overrepresented, when compared to the other Big Five queries. Surprisingly, keywords in the area of vaccines, vaccines' distribution, and vaccination campaigns – areas in which equity plays a central role – do not appear among the top 30 keywords, suggesting that further work, both theoretical and empirical, is needed to address and dissect this issue, developing evidence-based reflections, and guidelines for future preparedness.

Figure 3. Word cloud of the top 50 keywords in the 3rd query

Proportionality of measures: legitimation and procedures

The corpus on proportionality and COVID-19 is surprisingly small, and apparently clustered around two areas: concrete measures whose proportionality is in question (antibody testing, running ban, curfews) and wider implications (disaster preparedness, civil rights, conflict of duties). Scholarly work on proportionality seems to depend deeply on epidemiological data (Susceptible – Infected – Recovered models, contagion modelling). Of note, the Siracusa Principles (The American Association for the International Commission of Jurists 1985) appear in the top 30 keywords, suggesting that this document is still the normative framework of reference when discussing proportionality issues.

Figure 4. Word cloud of the top 50 keywords in the 4th query

Trust and trustworthiness

Trust appears to play a central role in the vaccination area (vaccination campaigns, vaccine acceptance, and vaccine hesitancy). Trust is also connected to a second relevant cluster of concepts, including risk perception, anxiety, and mental health. Finally, it definitely plays a role in literature targeting infodemics (misinformation, communication, conspiracy theories, media and social media).

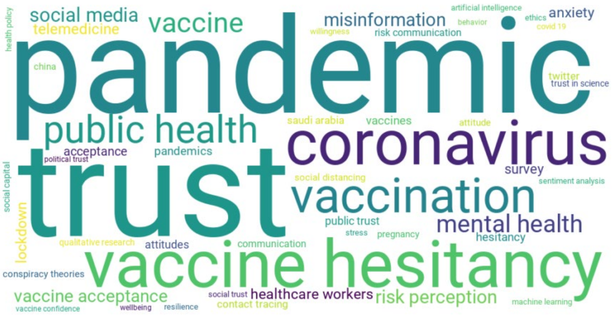

Figure 5. Word cloud of the top 50 keywords in the 5th query

Covid 19: a catastrophe and a chance to learn

One day in the hopefully not too distant future we will be looking back at the pandemic and try to understand how well we performed. This assessment should not be limited to parameters such as excess mortality, but also include questions such "How well did we handle ethical issues that arose?", "How well did we protect and care for our citizens, in particular the vulnerable and underprivileged?", "Did we manage to strengthen our democracies and the confidence of our citizens?" or "Have we understood how we can build resilient institutions and societies that can withstand crises?". This questioning will have a fundamental value, not only as a retrospective evaluation but most importantly as a prospective set of lessons to keep in mind not to be unprepared for future crises.

Tackling the pandemic requires the cooperation of many actors – healthcare institutions, governments, citizens, international organizations, companies and others. Working towards a joint understanding of who carries what responsibility to uphold our ethical core values and to resolve unavoidable moral tension and disagreement will be help us improve our pandemic preparedness so we can look confidently ahead. Smart digital tools can support leaders and decision-makers in keeping track of emerging ethical issues even when times become particularly challenging.

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5. Bidirectional risk and crisis communication

Chapter 5 tackles one very specific and very complex issue emerged during the COVID-19 pandemic: that of information, misinformation, and risk and crisis communication. It details the protocol of PubliCo, the core research project of this dissertation, adding further (unpublished) details on the strategy behind the concept. PubliCo stems from a simple intuition: in the context of a public health emergency, people need to have timely, precise and reliable information about what is happening, while policymakers need some sort of feedback informing them about what people knows about the crisis, how different strata of the population are faring in this scenario, and how they are receiving eventual safety measures. PubliCo is both a novel concept of risk and crisis communication, and a platform embedding and applying this concept, based on the notion of bidirectional risk and crisis communication, with quite some emphasis on citizen science and open science. It includes a quantitative component (PubliCo survey), used to gauge public perception and to provide personalized feedback based on selected scores; a qualitative component (PubliCo Diaries), fundamental to ‘add meaning to the size’ of the phenomena we observed, enriching the data and suggesting new hypotheses; a citizen science component (PubliCo Analytics), an interface through which everyone can play with the data, read reports that help understanding and contextualizing them, and make their own hypotheses. The first part of this chapter presents the concept and the implementation strategy; the second details in depth the methodological approach used to define the content of the survey we developed for COVID-19; the third is a convenient decalogue specifying how the information feedback for the public should be written.

PubliCo. A protocol for a new risk and crisis communication platform to bridge the gap between policy makers and the public in the context of the COVID-19 crisis

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Abstract

Background

Since the end of 2019, COVID-19 has had a significant impact on citizens around the globe. As governments institute more restrictive measures, public adherence could decrease and discontent mount. Providing high-quality information and countering fake news is important. But we also need feedback loops so that government officials can refine preventive measures and communication strategies. Policy-makers need information – preferably based on real-time data – on the public's cognitive, emotional and behavioural reaction to public health messages and restrictive measures. PubliCo aims to foster effective and tailored risk and crisis communication as well as an assessment of the risks and benefits of prevention and control measures, as their effectiveness depends on public trust and cooperation.

Objective

Our project aims to develop a tool that helps tackle the COVID-19 infodemic, with a focus on enabling a nuanced and in-depth understanding of public perception. The project adopts a trans-disciplinary multi-stakeholder approach, including participatory citizen science.

Methods

We combine literature and media review and analysis and empirical research using mixed methods, including an online survey and diary-based research, both of which are ongoing and continuously updated. Building on real-time data and continuous data collection, our research results will be highly adaptable to the evolving situation.

Results

As of September 2021, two thirds of the tool we propose are up and running. Current development cycles focus on the analytics component, on user experience, and on interface refinements. We collected a total of 473 responses through PubliCo Survey, and 22 diaries through PubliCo Diaries.

Conclusions

Pilot data show that PubliCo is a promising and efficient concept for bidirectional risk and crisis communication in the context of public health crises; further data are needed to assess its function at a larger scale or in the context of an issue other than COVID-19.

Keywords

disease outbreaks, coronavirus, COVID-19 surveys and questionnaires, qualitative methods, health literacy, policy making, risk and crisis communication

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Introduction

Background

Since the end of 2019, COVID-19 has significantly impacted the lives of people around the globe. Beyond infections, disease and death, the global public has been exposed to increasingly restrictive policy measures. Within weeks or even days, measures evolved from recommendations, such as frequent handwashing, to more disruptive interventions, including social distancing, cancellations of social events, closure of schools, and closed borders. Public life and ways of socializing that were taken for granted have come to an abrupt halt.

Exceptional circumstances, like this pandemic, generally have significant short-, mid- and long-term consequences in social, economic and maybe cultural and political terms. Some issues have already emerged, including social isolation of vulnerable groups, panic buying and stolen supplies, or instances of reprimanding others for their "irresponsible" behaviour. While the gradual easing of containment measures eased frustration in parts of the population following the first wave, the re-instalment of restrictive measures may lead to mounting discontent and decreasing public adherence to containment measures.

In Switzerland measures have been less restrictive than in many other countries, yet more drastic dispositions are conceivable and legally covered by the Swiss Epidemics Law should the situation require them, including a general curfew, mandatory testing or the use of mobile phone data for surveillance purposes. During the first wave (March to June 2020), the Swiss population has generally supported measures. As the second wave unfolds, however, the debate about public health measures like contact tracing, limits on visiting nursing home residents, home office, etc. has intensified.

"Anti-corona" demonstrations in several cities, gatherings of hundreds of people celebrating the end of the lockdown or organized "illegal" soccer games were among the first signs of resistance to public health measures (swissinfo.ch 2020). In order to effectively manage the current pandemic crisis, we must better understand how the Swiss public perceives public health measures taken and concerns they have about the pandemic and the government's response to it.

Information gaps

While governments are trying to steer through this crisis as cautiously as possible, the public is grappling with how to interpret what is happening. Communication is therefore key. Existing literature suggests that effective health communication can help enhance positive outcomes of public policy (Lee and Basnyat 2013b; Sandell, Sebar, and Harris 2013a). Importantly, the exposure to focused health campaigns in the context of epidemics has proven as an efficient tool not only to increase epidemic-related knowledge, but also to foster the adoption of recommended health behaviours (Ning et al. 2020; Lin et al. 2014).

While international organizations, national governments, public health authorities, scientific institutions and high-quality media are trying to inform the public as responsibly as possible, many other information sources of questionable credibility exist across media platforms all over Europe. Formal and informal opinion groups share content from these sources and influence public opinions in problematic ways, e.g., by blaming specific social and ethnic groups for the pandemic or by encouraging defiance of public health recommendations. Some media draw on dystopic pictures and morally loaded language, using war metaphors and reproaching those who voice doubts and criticism, which leads to polarization and an affectively charged debate producing strong counterreactions rather than factual and nuanced public deliberation (Semino 2021). This situation has led the WHO to warn of an "infodemic", wherein too much information of mixed quality make it hard for people to find reliable information (WHO 2020c). The WHO and other public health agencies are working on refuting myths regarding, e.g., false preventive measures and false cures, through fact checks of social media and writing responses (WHO 2020a).

However, providing high-quality information and countering fake news is not enough. Policy-makers also need feedback loops to give them real-time data on the public's cognitive, emotional and behavioural reaction to public health measures, allowing them to continuously refine and adjust preventive, control and containment measures and communication strategies.

A better understanding of the population's reaction to mitigation measures would allow better estimation of their potential effectiveness, influencing both communication strategies and policy choices (Plough et al. 2011; van der Weerd et al. 2011). It would also help to understand to what extent policy decisions match with citizens' moral values and preferences regarding, e.g., the allocation of scarce medical resources, contact tracing, or obligatory mask wearing (Kaplan and Baron-Epel 2015). Finally, understanding how different segments of the population perceive both the pandemic and public health measures is vital, as both disproportionately affected social groups that were already vulnerable before the pandemic (Adams-Prassl et al. 2020). How do, for example, frontline healthcare workers, older people, the chronically ill, or the economically vulnerable cope with the pandemic and mitigation measures? Given the limitations of "one size fits all" approaches to mitigation measures, local and subgroup data are critically needed to develop more efficient strategies (SteelFisher et al. 2012).

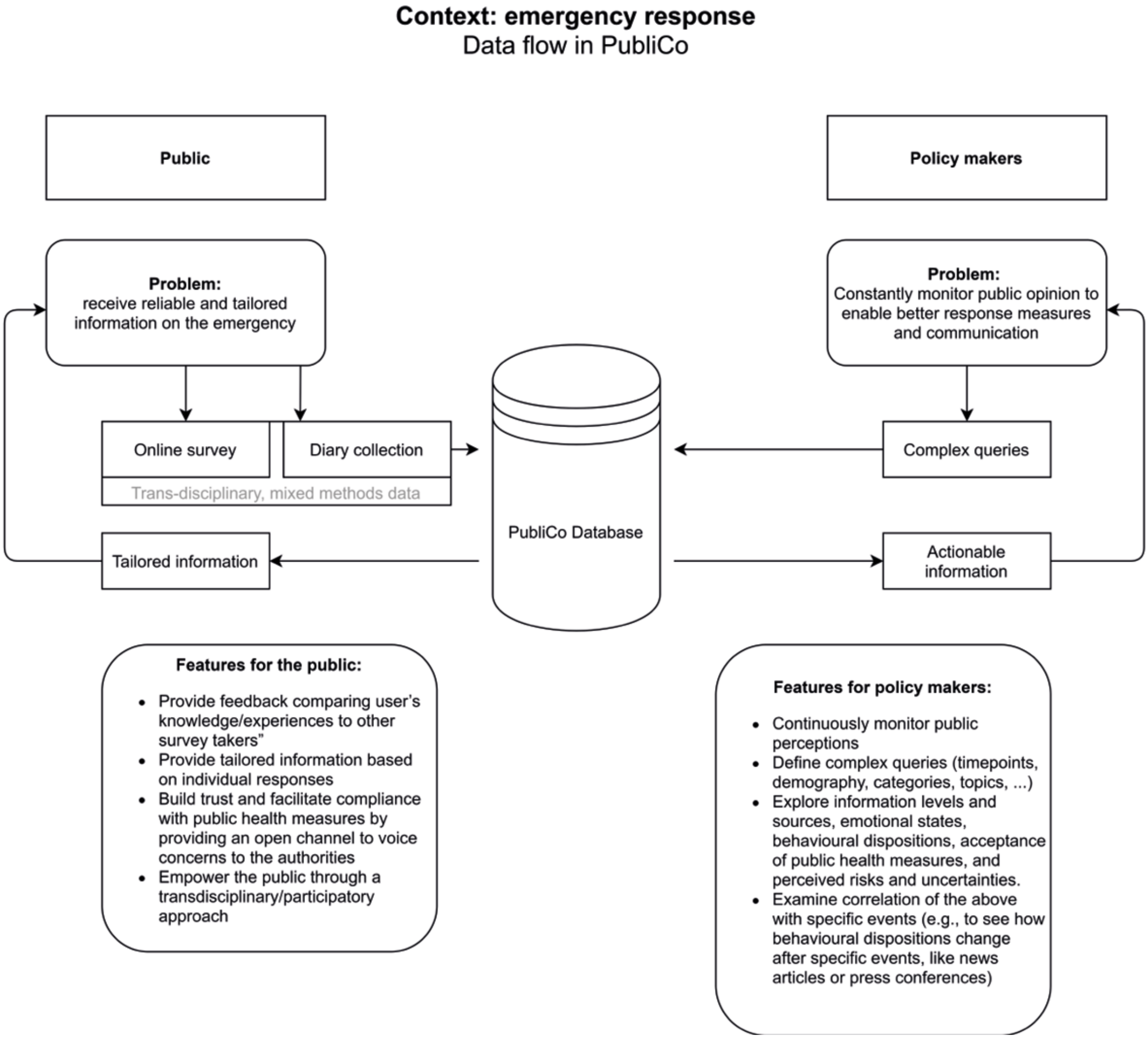
So far, there has been mainly "one-way communication". We know little about different subgroups' understanding of the situation and readiness to comply with policies, and how this is affected by their preferred information sources. Cross-sectional opinion polls (SRF 2020; tagesschau.de 2020; Betsch et al. 2020) encounter important limits in rapidly evolving situations – they are resource-intensive and limited in scope, their items are typically designed in a top-down way, they struggle with high non-response rates and provide snapshots rather than continuous monitoring (Kaplan and Baron-Epel 2015). Consequently, policy makers might rely on a suboptimal picture of reality in order to make their choices, and some citizens may feel that large demonstrations are the only way to make themselves heard. Even if the majority of the public support public policies and cooperate with them, this consensus may become fragile in the future if authorities disregard misunderstandings, concerns or unrest in certain segments of the population. Better monitoring of public perceptions would enable better communication and more effective containment measures that reduce collateral damage to society.

However, such monitoring must be done in a way that citizens do not perceive as unwanted surveillance but rather as an initiative that invites their active input and values their views and opinions.

Aims

PubliCo seeks to address these gaps. It is an experimental online platform built on a strong participatory citizen science component that will serve three purposes:

1. Collecting real-time data on COVID-19-related public perception;
2. Providing tailored, timely and reliable information to the public;
3. Facilitating well-targeted health policy-making based on the theory that successful communication, public understanding and consent reinforce the effectiveness of public health measures (Sandell, Sebar, and Harris 2013b; Lin et al. 2014; Lee and Basnyat 2013a).



Features for the public:

- Provide feedback comparing user's knowledge/experiences to other survey takers"
- Provide tailored information based on individual responses
- Build trust and facilitate compliance with public health measures by providing an open channel to voice concerns to the authorities
- Empower the public through a transdisciplinary/participatory approach

Features for policy makers:

- Continuously monitor public perceptions
- Define complex queries (timepoints, demography, categories, topics, ...)
- Explore information levels and sources, emotional states, behavioural dispositions, acceptance of public health measures, and perceived risks and uncertainties.
- Examine correlation of the above with specific events (e.g., to see how behavioural dispositions change after specific events, like news articles or press conferences)

Figure 1. PubliCo conceptual structure: after completing a short survey (PubliCo Survey), citizens can receive information tailored to their needs. Users can also register as citizen scientists and contribute diaries (PubliCo Diaries).

Policy makers can study the information provided by citizens in order to conceive, deploy and evaluate more efficient mitigation and containment measures (PubliCo Analytics).

Methods

Concept

The project combines analytical work and empirical studies using mixed methods and strong citizen science components in order to deliver a functional platform composed of three main elements: PubliCo Survey; PubliCo Diaries, PubliCo Analytics.

PubliCo Survey will be the main source of quantitative information. Based on demographic characteristics and scores on selected subscales, citizens will obtain information specific to their needs. For example, people living in border regions will receive information about neighboring countries, and people with children will receive information about safety measures in schools. The survey will be ongoing, providing real-time data on public perception and readiness to cooperate with public health strategies.

PubliCo Diaries will be the main source of qualitative information. Qualitative solicited diaries can provide "unique insights into the life-worlds inhabited by individuals; their experiences, actions, behaviors, and emotions and how these are played out across time and space" (Milligan and Bartlett 2019).

The diary approach empowers citizens to integrate their personal experiences and perceptions (Harvey 2011, 675) while remaining in control not only of the content described but also of the pace and time of data collection (Milligan and Bartlett 2019, 1451). In this way, this participatory method allows the involvement of citizens in the research process and the visualization of everyday negotiation processes in real time due to the immediacy of documentation (Milligan and Bartlett 2019, 1449; L. Hyers 2018, 24).

Users will register as citizen scientists and keep a weekly diary in which to record their reflections on how COVID-19 and related policy measures affect their daily routine, social practices, values and priorities. Citizen scientists may also keep their diaries offline or record audio files and have the text entered by project staff afterwards so that segments of the population that don't have time to keep a written diary or are less tech-savvy can participate. In this way, PubliCo Diaries attempts to reach diverse groups of citizens currently encountering different personal situations and possibilities (e.g. pregnant women, older people, people on short-time work, youth or people with a migration background). These texts will provide information about meaning, plus new insights on emerging, unforeseen aspects taken up by the diary authors. Finally, qualitative analysis of the diary data will inform the revision or generation of new survey items.

PubliCo Analytics will be the "access door" to the data collected through the survey and the diaries. It will provide information to be used for analyses directed to policy-makers regarding information levels, behavioral dispositions, emotional states, moral preferences. It also allows analysis of correlations of, e.g., vaccine prioritization preference and demographic sub-groups or support of preventive measures and COVID-19 experience. Finally, PubliCo Analytics will contain thematically focused policy briefs, in which we contextualize the data, interpret core findings, and make recommendations.

Ethics approval

As assessed by the Cantonal Ethics Committee of Canton Zurich (KEK), PubliCo does not fall under the scope of the Swiss Human Research Act (BASEC Nr. 2020-02917, 15th of December 2020, signed by Peter Meier-Abt and Peter Kleist). Our risk assessment and data protection plan were also reviewed and approved by CEBES, the institutional review board of the IBME at the University of Zurich (CEBES Nr. 2020-13, 15th of December 2020, signed by Markus Christen).

Funding

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Development

Developing the PubliCo platform involves work on three components:

- Development of PubliCo survey and user feedback;
- Realization and testing of the platform;
- Definition of analytic capabilities of PubliCo analytics;

PubliCo Survey and user feedback

In order to define the content of the survey and user feedback we adopted a threefold strategy: identify the kind of information people look for through the analysis of Google Trends data, map the information available in the media through Natural Language Processing (NLP) on news from major media outlets, and determine the focuses of COVID-19 related behavioural and social science research (BSSR) assessing the content of the data collection instruments for COVID-19 compiled by the NIH Office of Behavioral and Social Sciences.

The analysis of Google Trends data on searches about COVID-19 performed in Switzerland between January and July 2020 displays a high diversity in information consumption patterns, that vary greatly depending on the Canton of residency. Swiss residents may therefore welcome a system like PubliCo, which delivers personalized information (Jafflin et al. 2021, 6).

We identified the following categories of queries regarding the pandemic and its effects:

- Georeferenced information
- Information from official sources (e.g: WHO, Federal authorities)
- Quantitative information
- News and updates
- Medical information
- Tips

In order to understand how the media discuss and frame COVID-19 in Switzerland, we used Factiva, a news monitoring and search engine developed and owned by Dow Jones that has access to full text articles published by major media outlets worldwide. We gathered and downloaded all the news articles published between January and July 2020 on Covid-19 and Switzerland.

Natural Language Processing (NLP) and analysis of the frequencies of lemmas (Spitale, Merten, and Biller-Andorno 2020b) revealed some differences across languages. The analysis of German lemmas indicates a public discourse focused on quantitative aspects of the pandemic; the French subcorpus focused on describing the pandemic and its effects on people; the Italian subcorpus focused more on cases and fatalities; the English subcorpus seems dominated by information reported from other sources, which makes sense as English is not an official language of the Confederation, and by many lemmas like "company", "group", "market", suggesting greater attention to the economic and financial impact of the pandemic (Jafflin et al. 2021, 7).

All the subcorpora provide the following macro-categories of information:

- georeferenced information (information specific to countries, Cantons or cities);
- general information about the pandemic and about the virus;
- reports from authorities and official bodies;
- quantitative information.

The NIH Office of Behavioral and Social Sciences released a document listing "data collection instruments, including surveys, for assessing COVID-19-relevant BSSR domains for clinical or population research" (NIH Office of Behavioral and Social Sciences Research 2020). Reviewing the surveys listed in the document we identified 6 main topics of interest: financial impact, social practices, behavioral dispositions, moral preferences, emotional state and cognitive understanding (Jafflin et al. 2021, 10).

A comparison between information consumption patterns, information available in the media, and BSSR research interests identified 5 categories of information to collect and to provide through PubliCo:

- Demographics;
- Cognitive understanding;
- Behavioral dispositions;
- Emotional state;
- Moral orientations.

Citizen scientists will be involved in the validation of the survey and of the information we intend to provide. This will be accomplished through the web-based project builder of the Citizen Science Center Zurich (Citizen Science Center Zurich 2020).

Realization and testing of the platform

The PubliCo platform is being developed in cooperation with Belka, a software house based in Trento/Munich, with extensive expertise in user experience design and development. The platform is web-based, mobile first, and is built on a stack of open source software (React, SurveyJS, Typescript, Django, MariaDB, Docker, CicleCI, NGINX).

Particular attention is being devoted to the development of PubliCo Diaries, the interface through which registered citizen scientists can contribute their diaries. Early users are involved in providing bottom-up feedback to refine and improve the interface. User experience testing will help ensure the platform is accessible to a large part of the Swiss population.

Another critical activity on the platform is the development of a backend for researchers, allowing non-technical staff to view, add and modify surveys, information for the users, translations and analytics components in an intuitive and collaborative way. The content management system fully supports a multilingual interface. The final aim in this sense is to develop a tool that can be easily deployed and maintained everywhere, with little or no knowledge of the code running behind the interfaces.

Definition of analytic capabilities of PubliCo analytics

Results from the online survey will be analyzed in multiple ways. Users will have direct feedback for certain variables (e.g: information level, behavioral dispositions), including scores and official information based on responses to knowledge questions but also basic descriptive statistics (means and frequencies) for all users and specific sub-groups or respondents from specific cantons.

In addition, through PubliCo analytics, researchers and policy makers will be able to answer complex questions like "Are people who know someone who got infected by COVID-19 more likely to get vaccinated?" "How would people who have personal experience with COVID-19 prefer the vaccine to be distributed?" Queries can restricted to specific subgroups (e.g. age, residency, level of education).

Project researchers will also analyze results for periodic policy briefs. Questions to be examined will vary over time and will include basic descriptive statistics for the different domains included in the survey (knowledge, emotional state, behavioral dispositions and moral preferences), sub-group analyses by geographical area and target group, and correlation analyses. Questions to be examined through correlation analysis include:

What is the relationship between participant knowledge and willingness to comply with public health restrictions?

What is the relationship between participant knowledge and emotional state?

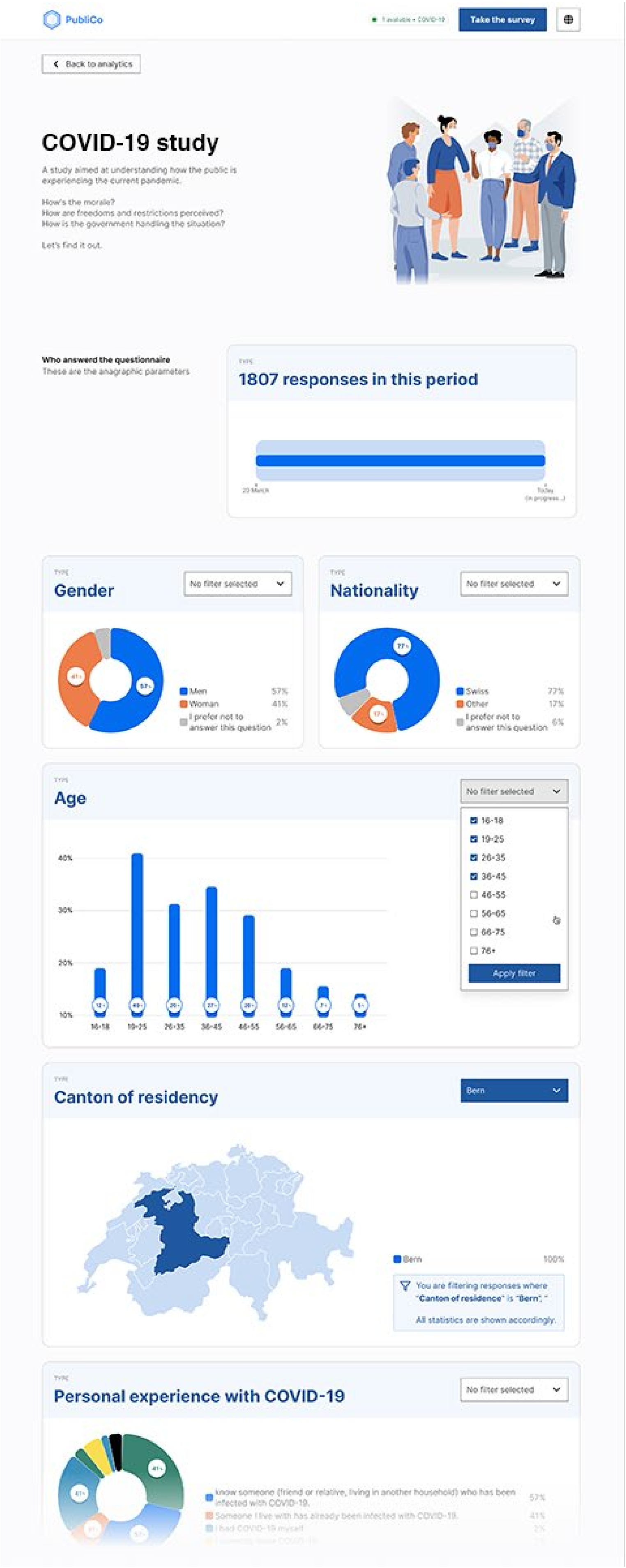
What is the relationship between participant's emotional state and their willingness to comply with public health restrictions?

What factors influence participants' moral preferences?

These and other questions will be analyzed using regression analysis with a significance level of $\alpha = 0.05$.

The diary narratives will be anonymized and analyzed in conjunction with the ongoing data collection by means of thematic analysis (L. L. Hyers 2018) using the Software MAXQDA (Woolf and Silver 2017).

Selected data will be displayed in PubliCo Analytics in a visually appealing form (e.g. infographics, live maps), as shown in Figure 2.



COVID-19 study

A study aimed at understanding how the public is experiencing the current pandemic.

How's the morale?
How are freedoms and restrictions perceived?
How is the government handling the situation?

Let's find it out.

Who answerd the questionnaire
These are the anagraphic parameters

1807 responses in this period

Gender

No filter selected

🟦 Men	57%
🟧 Woman	41%
⬜ I prefer not to answer this question	2%

Nationality

No filter selected

🟦 Swiss	77%
🟧 Other	17%
⬜ I prefer not to answer this question	6%

Age

No filter selected

☑ 16-18
☑ 19-25
☑ 26-35
☑ 36-45
☐ 46-55
☐ 56-65
☐ 66-75
☐ 76+

Canton of residency

Bern

🟦 Bern	100%

You are filtering responses where "**Canton of residence**" is "**Bern**". "

All statistics are shown accordingly.

Personal experience with COVID-19

No filter selected

🟦 know someone (friend or relative, living in another household) who has been infected with COVID-19.	57%
🟧 Someone I live with has already been infected with COVID-19.	41%
🟦 I had COVID-19 myself	2%

Figure 2. A high level mock-up of PubliCo Analytics. Different kinds of survey data are bind to different visualizations. Visualizations can also be used to dynamically select a subset of the dataframe (e.g: selecting only specific demographic variables). The interface is meant to be informative, clear and comprehensive also for a lay public. Every visualization is accompanied by an explanatory note.

Advanced analytics will be employed whenever possible (NLP for text elements, predictive modelling of, e.g., public behavior in case of new measures taken). Many passages, from the analysis of diaries to the automated analysis of selected subscales, will be automatized by means of NLP and other related AI applications. These techniques will ensure that the platform is more cost effective and that results of analysis and actionable information are available faster.

Data collection will be adapted to how the situation evolves, taking up emerging themes (e.g. vaccine distribution; balancing work requirements and protection of persons with risk factors). Core findings and recommendations will be published in thematically focused policy briefs.

Results

Data collection

Data collection for PubliCo Survey started with a pilot phase (December 2020 to April 2021), during which we collected analytics on how the platform and its different tools are used. For this purpose, we used a shorter version of the PubliCo survey, evaluated by citizen scientists through Citizen Science Center Zurich. This passage yielded more bottom-up input before deploying the full survey.

Data collection for PubliCo Diary started during the pilot phase as well. Participants were given a brief guide to the diary method, which informed them about the openness of the method (e.g., without concerns about spelling and grammar). The guide asked them to jot down their experiences and thoughts from the beginning of the pandemic to the current day and their everyday worries, emotions, risks, experiences, decisions and actions during and/or after the pandemic in at minimum a weekly rhythm for a duration of at least 4 weeks. This will allow "to document changes in values, attitudes, knowledge and behavior" (Constant and Roberts 2017).

In order to increase the user base, after the pilot phase PubliCo is being disseminated through:

- General media through featured articles in order to reach the general population;

- Mailing lists of the Universities of Zurich and Basel in order to reach undergraduate and graduate students;
- Facebook groups in order to reach selected target groups, including migrants and parents;
- Teachers' associations in order to reach high school students;
- Participants of the Swiss branch of the DIPEx International Study on COVID-19 in order to reach people who had direct experience of COVID-19;
- A demoscopic company that will solicit a representative sample for comparative purposes.

The outboarding section also invites the users to share the tool further via social media, email or similar systems, and to register as citizen scientists for the PubliCo Diary component. We will also investigate possibilities of disseminating through official channels, like the automatic SMS sender of the Federal Office of Public Health.

As of September 2021 we collected a total of 473 responses through PubliCo Survey, and 22 diaries through PubliCo Diaries. Data collection will be iterative and will proceed for at least two years. We expect the tool to be refined and enhanced as data collection and analysis moves forward. Because of the design of the tool, data saturation will be determined a posteriori analysing the demographic data of surveys and of diary users. The current version of the tool is available at www.publico.community.

Availability of data

Preliminary and intermediate data

The Google trends dataset used in the definition of the survey component is available through our Zenodo repository (Spitale, Biller-Andorno, et al. 2020). The software used for the analysis of the Factiva corpus is available through our Zenodo repository (Spitale, Merten, and Biller-Andorno 2020a). The raw results of the analysis of the Factiva corpus are available through our Zenodo repository (Spitale, Merten, and Biller-Andorno 2020b). Due to copyright restrictions, the Factiva corpus is available through Factiva.

Research data

Data generated from PubliCo will be available through the PubliCo Analytics interface. Diary data are available upon request.

Discussion

Ethics and dissemination

One aim of PubliCo is to deliver personalized information in the context of public health emergencies. However, providing personalized information can be potentially problematic. Feedback on knowledge-based questions simply involves notifying users of wrong answers and giving access to reliable sources, like the WHO or official information outlets (EU vs Disinformation 2020). Some uneasiness remains around making assumptions about citizen's informational needs and possibly contributing to knowledge "bubbles". Providing personalized information from subscales regarding emotional response, moral preferences or mental wellbeing is more challenging. For these topics we will provide a comparison between individual scores and sample means. In this sense, it is fundamental to clarify the descriptive nature of the scores without any claims as to what the norm should be (is-ought problem). The final strategy needs to be defined with expert advisors and citizen scientists after evaluating potential outcomes.

The Swiss Cantons are affected in different ways by the COVID-19 pandemic. Our approach, comparing geo-located data, might reveal differences in behaviours and attitudes that could correlate with the course and the severity of the pandemic. Because of this, we will collect some demographic information (personal data, potentially also sensitive as defined in the Law on Information and Data Protection (IDG) par. 3 of the Canton of Zurich) and some information about personal philosophical or religious beliefs (sensitive data as defined in IDG par. 3).

The potential harms generated by the project, assessed in Table 1, fall in two categories: re-identification (and thus attribution of specific opinions to specific persons) and morally problematic questions.

Potential event	Potential consequences	Type of harm	Severity (1-5)	Likelihood (1-5)
Re-identification of a participant	Participants can feel betrayed by the data controller and lose trust in research/society	Psychological	2	1
Re-identification of a participant	Participants with controversial opinions could lose their jobs when these are considered particularly	Economical	3	1

	dangerous by their employers			
Re-identification of a participant	Participants with controversial opinions could be rejected and isolated from the societies of which they are part	Social	3	1
Re-identification of a participant	Participants with controversial opinions could be physically assaulted because of their opinions	Physical	5	1
Morally problematic questions	Participants can be upset when asked about morally problematic topics (e.g. allocation of scarce resources) especially if directly touched by the issue at stake	Psychological	2	3

Table 1. Risk assessment of PubliCo.

The most prominent category of risks is connected to re-identification of participants. To minimize chances of this, the survey component is completely anonymous by design (not even the IP address is collected) and the diary component is pseudonymous by design (we can attribute diaries to users, but we cannot attribute users to persons). The only remaining concrete risk for re-identification is posed by what users could write in the diaries. Because of this, we take extra care in planning the access, use and management of this category of data: no personal identifiers are collected upon registration, diary text is accessible upon request to trusted third parties (e.g: research institutions), and the content is manually checked for full anonymity beforehand. We are confident that the instrument is safe from a data protection point of view.

All the data will be stored in a virtual machine hosted in the data centre of the University of Zurich with access restricted to the project members. The chances of identification, in the eventuality of a data leak, are very low.

In order to mitigate the second category of risk we are discussing the whole survey tool with expert advisors and citizen scientists in order to get double feedback on the issues involved. That said, the impact would still be low, and more importantly the distressed user can interrupt or end participation at any time.

The very nature of this project implies another general risk: in a less democratic context the tool we are developing could be used for social control. This is a potential risk we cannot mitigate for other countries. For Switzerland, the whole infrastructure of the project is built keeping in mind a transparent and democratic approach, important in general in the scientific enterprise, but fundamental in a context in which the data yielded from the system are used in order to make decisions impacting the public.

Overall, participants do not have an immediate personal benefit beyond the insights gained through the survey experience and feedback, but do have a long-term community benefit resulting from the tool being used to deploy public health measures that consider and take into account their preferences. Therefore, we consider the risk-benefit balance justifiable.

Open science by design

We believe that adopting a democratic, bottom-up approach to designing and developing PubliCo would greatly improve public perception of the project, while allowing us to tackle urgent and unforeseen issues (Smart et al. 2019). As such, every component of PubliCo will be publicly available: the research project, the intermediate datasets and the software used to compile them, the source code, the raw data and the interpretative briefs. The only data that will be subject to manual check before release is the raw text of the diaries, as stated above.

This setup will increase trust in the project, encourage secondary use of PubliCo data, and ease the implementation of the tool in other countries.

Limitations

This design has two main limitations. Our approach focuses on public perception rather than on observational data of real practices. There may be discrepancies between opinions, attitudes and behavioral dispositions and what people actually do. On the other hand, we think much insight is to be gained already from what people are in principle agreeable to or what they will consider inacceptable.

The second limitation regards the information to provide at the end of the survey: for some topics, e.g. the concrete risk posed by COVID-19, it is (still) difficult to find solid figures and the way they are communicated can generate problems and misunderstandings. In this sense we have opted for a different approach: users will be pointed first to the official information provided by the Federal Office of Public Health, and secondly (depending on their scores in cognitive understanding) to PubMed queries designed to yield systematic reviews or meta-analyses. This way, following once again an open science spirit, citizens will be able to access the relevant literature.

Conclusions

Pilot data show that PubliCo is a promising and efficient concept for bidirectional risk and crisis communication in the context of public health crises, as it can reach and engage different segments of the Swiss population, collecting and providing information at the same time. Further data are needed to assess its function at a larger scale or in the context of an issue other than COVID-19.

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PubliCo: creating the survey

UNPUBLISHED MATERIAL.

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To define the content of the survey we examined three categories of sources: Google Trends searches, publications in the general media (grey literature), and existing surveys. The aim was to capture what kind of information people are looking for, what kind of information is available in the media, and what is the focus of COVID-19 related BSSR research.

Google trends data

We searched for queries using the keywords "Coronavirus + covid + 2019-nCoV + SARS-CoV2" executed in each one of the Swiss Cantons and on Switzerland as a whole between 27/07/19 and 27/07/20. Data extraction was performed on the 27 of July 2020. Table 1 reports the structure of the query as suggested by Mavragani and colleagues (Mavragani, Ochoa, and Tsagarakis 2018).

Query	Coronavirus + covid + 2019-nCoV + SARS-CoV2
Query type	keyword
Timeframe	27/07/19 - 27/07/20
Date of search	27 07 2020

Data source	Web searches
Location	CH (by canton)
Query category	all

Table 1, structure of the Google Trends query

For the purpose of this study we analysed the normalized hits per Canton over time and the top searches associated to the keywords in our list, defined by Google trends as "terms that are most frequently searched with the term you entered in the same search session, within the chosen category, country, or region" (Google 2020).

The normalized hits per week allow to see a very general national trend in the need for information about a new phenomenon: the novelty of the outbreak explains the initial spike in February/March, after which the searches normalize around a new baseline. It is important to keep in mind, as pointed out by several studies on infoveillance, that Google Trends does not provide raw numbers, but only normalized hits. The normalization of data, as Mavragani and Ochoa point out, "indicates that the values vary from 0 to 100. The value 0 does not necessarily indicate no searches, but rather indicates very low search volumes that are not included in the results. The adjustment process also excludes queries that are made over a short time frame from the same internet protocol address and queries that contain special characters." (Mavragani and Ochoa 2019).

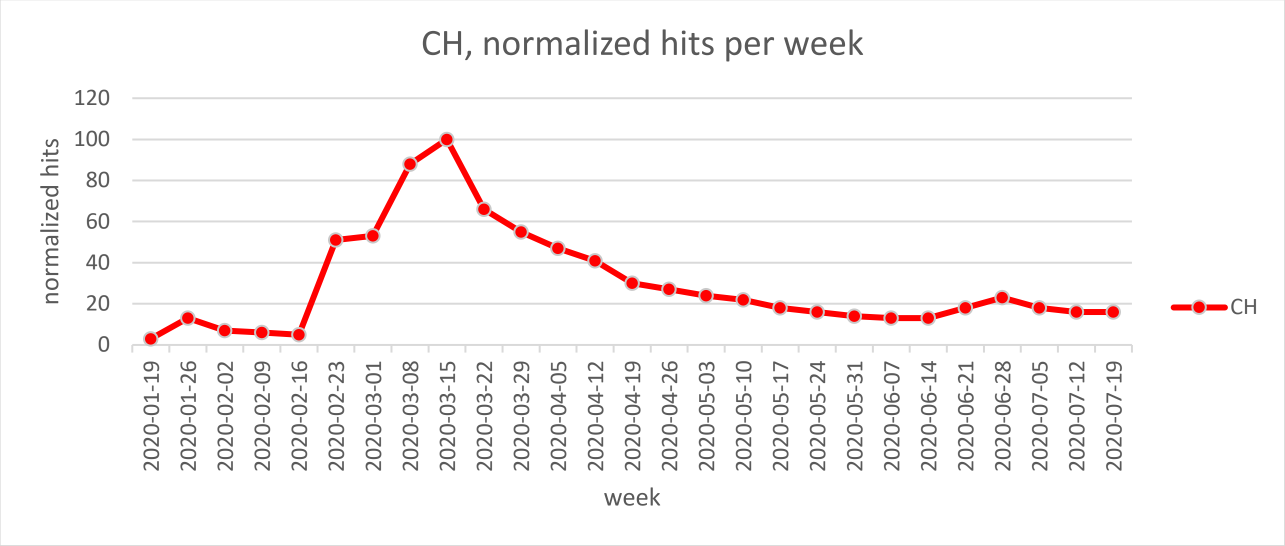

Figure 2, normalized hits per week for COVID-19 searches in Switzerland

It is worth noting the temporal distribution of the normalized hits per week: after the initial peak (mid-february to mid-april) the count seems to stabilize. A working hypothesis for interpreting this trend in information consumption is that people needed a lot of "ontological" information about a new phenomenon when it appeared (e.g: "what is coronavirus?", "what are the symptomps?"); it is reasonable to suppose that in the post-peak phase the information need steered towards live updates, new regulations and provisions, travel limitations and so on ("management information").

Top associated searches are more interesting, as they allow to see what users were looking for when looking for terms comprised in the search strategy.

We hand-coded the top searches, assigning to each one of them a category; categories were defined bottom-up, during the coding process. Table 2 lists the categories we defined, the explanation, and some examples of searches belonging to that category.

Category name	Explanation	Examples
geographical reference (place of residency)	Country, region or city the searcher lives in	"covid Suisse" "Aargau coronavirus" "coronavirus Zürich"
geographical reference (other place)	Country, region or city that differs from the origin of the query	"Deutschland coronavirus" "Lombardia coronavirus" "coronavirus Luzern"
official body	World health Organization, Federal Office for Public Health	"bag coronavirus" "coronavirus ofsp" "who coronavirus"
quantitative information	Number of cases, number of deceased, other statistics	"worldometer coronavirus" "coronavirus statistics" "cas coronavirus suisse"
news	News, either specific to a place or general.	"coronavirus news schweiz" "coronavirus ticino news" "rts coronavirus"
medical information	Information related to the diagnosis, treatment or outcome from a clinical point of view	"coronavirus symptome" "coronavirus sintomi" "coronavirus symptomes"
tips	Suggestions and advice	"coronavirus tipps" "coronavirus conseils"
live update	Live updates on the pandemic situation	"coronavirus update" "coronavirus schweiz aktuell" "coronavirus live"
general information	General information about the virus, the disease or the pandemic	"info coronavirus" "corona virus" "covid 19"

Table 2, categories, definitions and examples

The count of the categories of the top associated searches allows to understand what macro-topics have been perceived as most interesting (reported in table 3). Moreover, comparing the mean of the cantonal data (column 3) to the aggregated data for the whole Country (column 2) allows to see how some macro-topics can be considered important in some areas, but without emerging in the aggregated data. It follows that, especially in

Countries characterized by geographic, cultural and linguistic diversity as Switzerland, infoveillance studies using Google trends data need to be granular, using lower-level data aggregation strategies. The cantonal composition of the top associated searches is displayed in Figure 3.

Categories	CH, Google Trends aggregated data	CH, mean per canton	CH, min per canton	CH, max per canton	CH, SD per canton
geographical reference (place of residency)	9	7,23	1	11	2,83
geographical reference (other place)	5	3,38	0	6	1,98
news	3	2,12	0	4	1,18
quantitative information	1	2,04	0	4	1,56
general information	2	1,73	0	4	1,19
official body	1	1,04	0	2	0,60
medical information	2	0,92	0	2	0,63
live update	2	0,92	0	3	0,98
tips	0	0,54	0	1	0,51

Table 3, category count and descriptive statistics

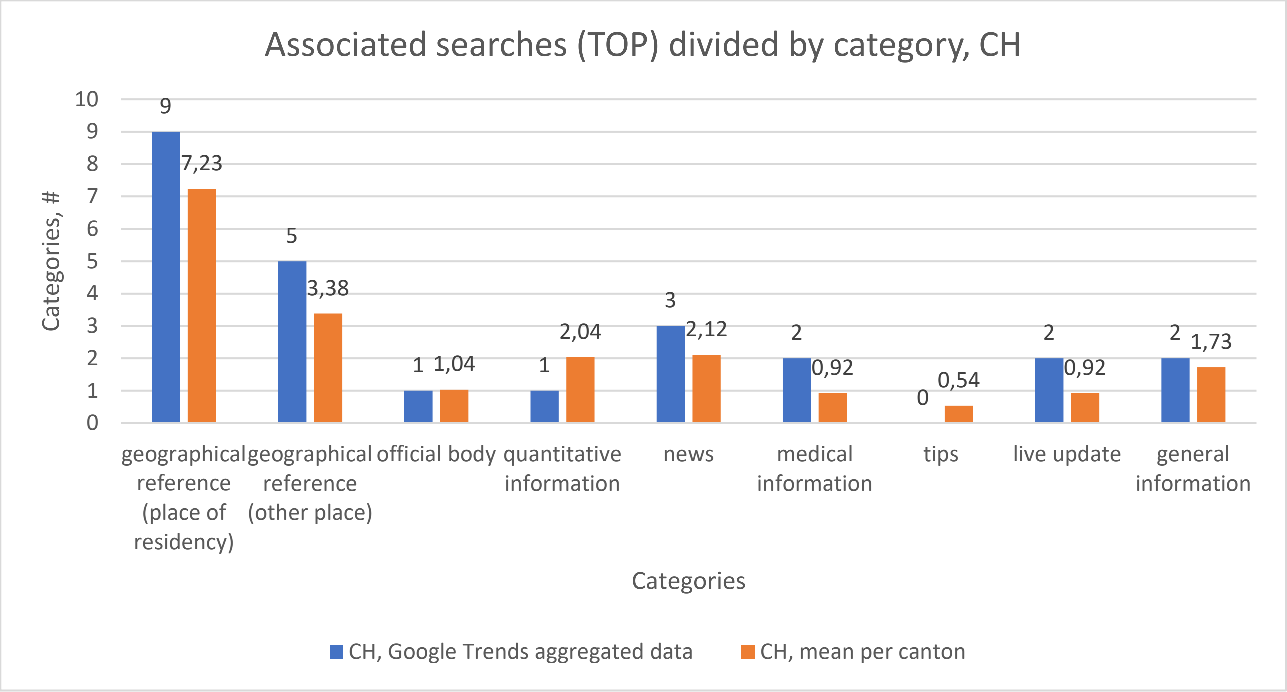

Figure 3, associated top searches, comparison between aggregated data (blue series) and mean of Cantonal data (orange series).

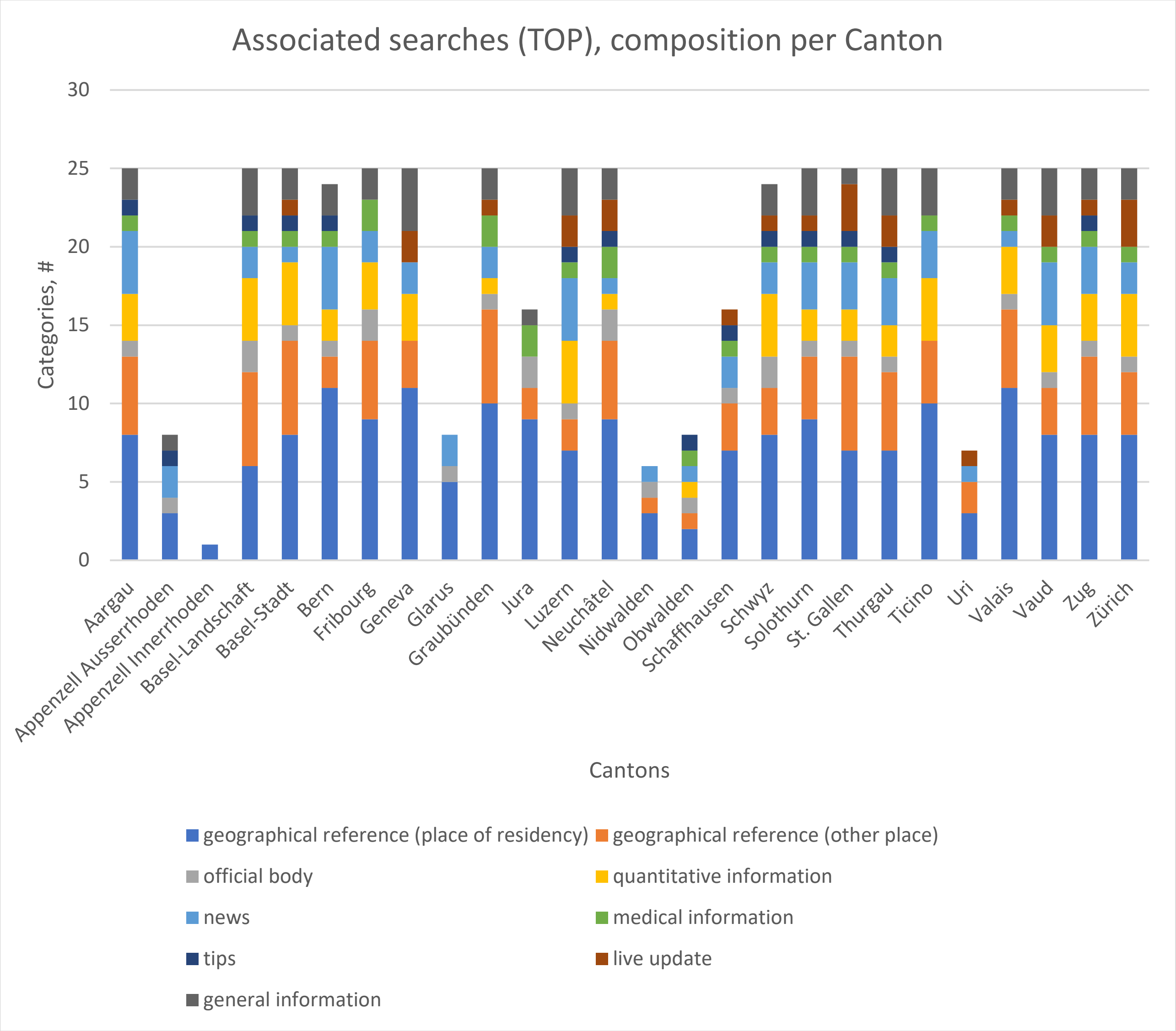

Figure 4, categorical composition of the top associated searches.

A final remark: these data are generated with an observational design, not in a controlled experiment. Many variables can influence the query composition and the information consumption. Nevertheless, the aforementioned differences in information consumption (summarized in Figure 2, per category, and in Figure 3, per Canton) are already sufficient to justify experimenting a system like PubliCo, allowing the delivery of personalized information. The data discussed here are available for secondary analyses (Spitale, Biller-Andorno, et al. 2020).

General media (or grey literature)

The analysis of large bodies of grey literature via text mining and computational linguistics is an increasingly frequent approach to understand the large-scale trends of specific topics (Cambria et al. 2013). We used Factiva (Factiva 2020b), a news monitoring and search engine developed and owned by Dow Jones, to gather and download all the news articles published between January and July 2020 on Covid-19 and Switzerland. Factiva allows a very granular definition of the queries, and moreover has access to full text articles published by the major media outlet of the world. The query has been defined as follows:

Syntax	Meaning
((coronavirus or Wuhan virus or corvid19 or corvid 19 or covid19 or covid 19 or ncov or novel coronavirus or sars) and (atleast3 coronavirus or atleast3 wuhan or atleast3 corvid* or atleast3 covid* or atleast3 ncov or atleast3 novel or atleast3 corona*))	Keywords for covid19; must appear at least 3 times in the text
and ns=(gsars or gout)	Subject is "novel coronaviruses" or "outbreaks and epidemics" and "general news"
and la=X	Language is X (DE, FR, IT, EN)
and rst=tmnb	Restrict to TMNB (major news and business publications)
and wc>300	At least 300 words
and date from 20191001 to 20200801	Date interval
and re=SWITZ	Region is Switzerland

Table 4, structure of the Factiva query

It is important to specify some details that characterize the query.

The query is not limited to articles published by Swiss media, but to articles regarding Switzerland. The reason is simple: a Swiss user googling for "Schweiz Coronavirus" or for "Coronavirus Ticino" can easily find and read articles published by foreign media outlets (namely, German or Italian) on that topic. If the objective is capturing and describing the information trends to which people are exposed, this approach makes much more sense than limiting the analysis to articles published by Swiss media.

Factiva's field "NS" is a descriptor for the content of the article. "gsars" is defined in Factiva's documentation as "All news on Severe Acute Respiratory Syndrome", and "gout" as "The widespread occurrence of an infectious disease affecting many people or animals in a given population at the same time"; however, the way these descriptors are assigned to articles is not specified in the documentation (Factiva 2020a).

Finally, the query has been restricted to major news and business publications of at least 300 words. Duplicate check is performed by Factiva. Given the incredibly large amount of articles published on COVID-19, this (absolutely arbitrary) restriction allows to retrieve a corpus that is both meaningful and manageable, listed in table 5. Figure 3 displays the linguistical and temporal distribution of the retrieved articles.

	Results	Duplicates	Included
EN	2030	662	1368
DE	4741	1816	2925
FR	861	222	639
IT	209	52	157

Table 5, results, duplicates and included per language

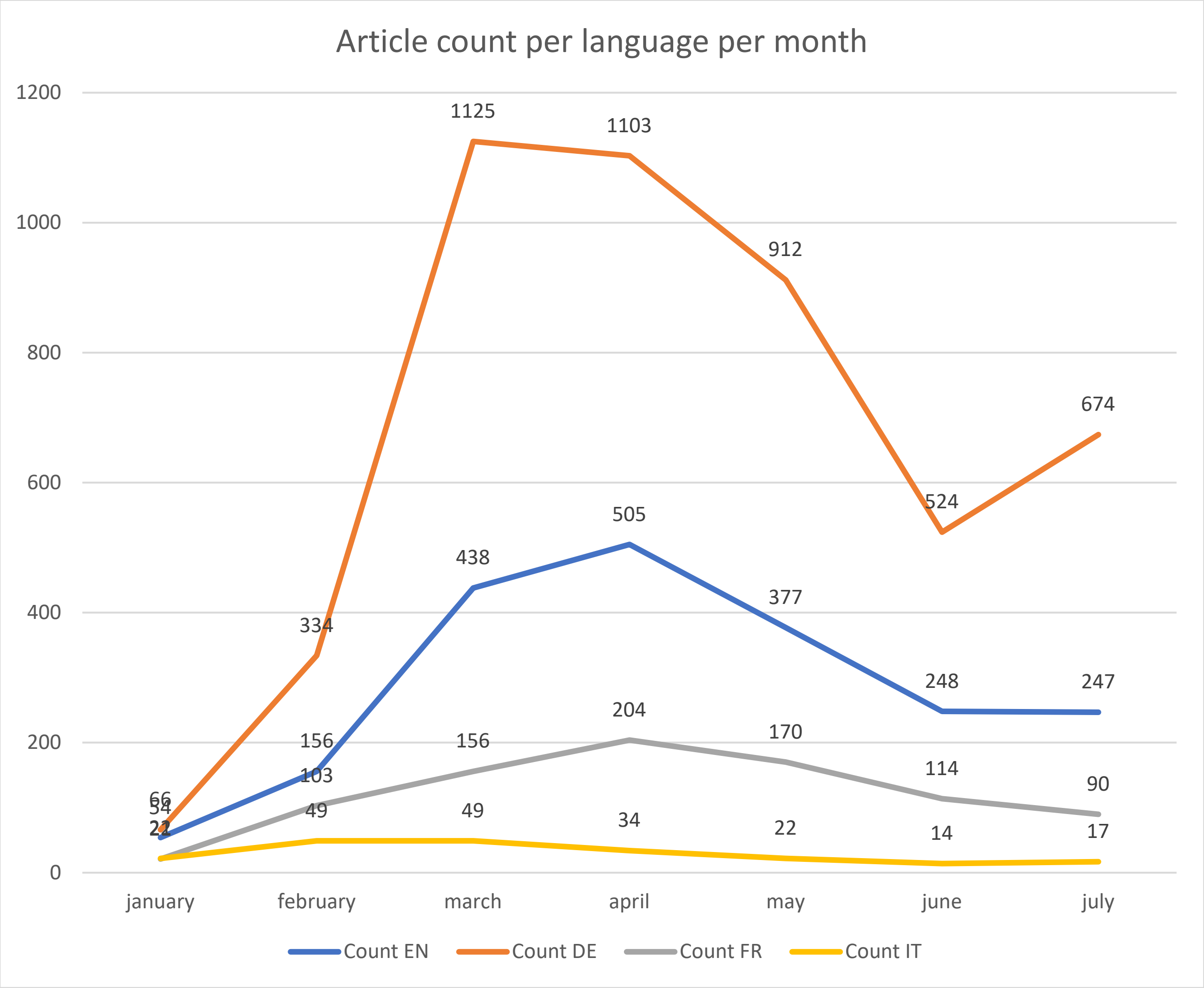

Figure 5, article count per month. blue: english; orange: german; grey: french; yellow: Italian

After batch-converting the RTF files retrieved from Factiva with unoconv in a unix environment, we analysed the content of the linguistic corpora using an ad-hoc Python pipeline (Spitale, Merten, and Biller-Andorno 2020a).

Being the Factiva export retrieved via manual downloads (UZH has no API access) it is rather dirty and unstructured, i.e. a set of files containing 100 articles plus the attached metadata. The first step was thus parsing the material. We wrote a Python parser that opens each one of the files and using regex rules identifies the relevant fields (article ID, language, date, title, Author and text), saves them in a new data frame and then exports it as a .csv file. This approach allows more refined manipulations of the text in the natural language processing pipeline, for instance limiting the analysis to a very specific time interval.

The NLP pipeline adopts a very simple approach, coherent with the purpose of this part of the study. The overall idea is to reduce the corpora to a list of concepts to be tracked over time and to be confronted with the results of the Google trends data analysis. We decided to use spaCy, a widely adopted Python library that together with NLTK represents the state of the art for NLP (Srinivasa-Desikan 2018; ExplosionAI GmbH 2021; spaCy 2020b). Moreover, spaCy supports over 59 languages, making it easier to replicate this section of the study in many different linguistical contexts. The Python script opens the text, tokenizes it, and then proceeds to lemmatization and named entity recognition.

Lemmas

Lemmatization and stemming are processes aiming to provide a first level of conflation of the text, reducing its complexity and allowing measurements and comparisons. Stemming is a fast process, reducing words to their root by eliminating suffixes. For example, the words “virus”, “viral”, “virulent”, “virology” share the common root “vir”. One important limit of stemming is that its focus is the removal of suffixes. In highly inflectional languages such as German, where for instance past tenses are created adding prefixes to the words, this approach would represent a big limitation (Willett 2006).

Lemmatization is another approach to text conflation. Being based either on rules or on lookup lists, it is more intense from a computational point of view, but also more precise. Moreover, it avoids the problem mentioned above for stemming in German, thus allowing to sort out a fundamental issue.

When lemmatizing with a lookup table approach, the algorithm confronts every token of a given corpus with the content of a lookup table which lists flexed forms and their corresponding non-flexed forms. The limit of this approach is that it is as good as the lookup table it employs, which needs to be as accurate and as complete as possible.

When lemmatizing with a rule-based approach, the algorithm reduces tokens to their non-flexed form using sets of rules that are language-specific and depend on the POS (part of speech) tag of each token. For example, if the token "going" is POS tagged as "verb", the relevant rule to apply would be something like "if the suffix is -ing, remove the suffix". Rule based lemmatizers can be very precise, can handle out of vocabulary words. The limit of rule-based approaches is that they require lots of computational power and thus are very slow (Plisson, Lavrac, and Mladenic 2004).

SpaCy provides lookup tables for efficient and rather precise lemmatizing in all the languages that are relevant for this project. We performed lemmatization on the subcorpora in German, French Italian and English in order to track the most common concepts discussed in the media and their trends in the first seven months of the pandemic.

Results are displayed in Tables 6, 7, 8 and 9 (20 most common lemmas and their trends, divided by language) and in Figures 5,6,7, and 8 (monthly trends of the 10 most common lemmas). The data presented here have been cleaned from non-meaningful lemmas such as common articles, verbs or interjections (e.g. "e", "essere", "il" in the Italian corpus) Nevertheless, the original dataset (prior to data cleaning) is available for secondary analysis (Spitale, Merten, and Biller-Andorno 2020b).

#	lemma	total	jan	feb	mar	apr	may	jun	jul	mean
1	prozent	10196	175	724	1572	2164	3112	730	1719	1456.57
2	million	7784	28	126	759	1420	3535	511	1405	1112.0
3	coronavirus	7064	323	1000	2530	1309	936	470	496	1009.14
4	schweiz	7041	219	383	2178	1328	1204	868	861	1005.86
5	euro	5113	15	138	572	725	2803	119	741	730.43
6	unternehmen	4092	33	175	914	856	1192	319	603	584.57
7	milliarde	4066	20	127	630	842	1241	263	943	580.86
8	mensch	3959	126	261	1227	964	600	357	424	565.57
9	schweizer	3911	87	289	1018	769	621	442	685	558.71
10	land	3494	65	305	933	694	685	449	363	499.14
11	woche	3486	54	180	1125	904	562	320	341	498.0
12	zahl	3451	69	307	950	854	582	284	405	493.0
13	fall	3396	163	473	1156	574	390	297	343	485.14

14	virus	3333	157	570	1145	589	430	177	265	476.14
15	person	3258	91	213	999	613	481	342	519	465.43
16	kanton	3234	27	189	1073	657	445	315	528	462.0
17	quartal	3193	7	46	122	680	1698	99	541	456.14
18	2020	2994	21	101	504	724	690	384	570	427.71
19	stark	2988	32	196	718	648	772	270	352	426.86
20	document	2946	62	176	764	639	540	342	423	420.86

Table 6, 20 most frequent lemmas in German

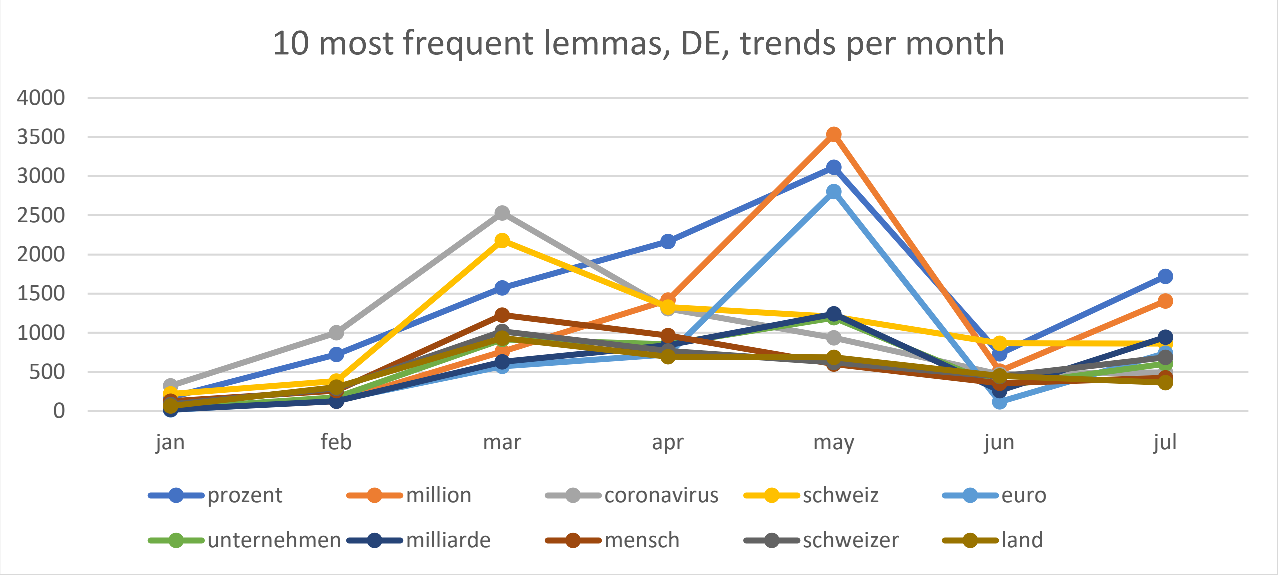

Figure 6, monthly trends of the 10 most common lemmas, German

#	lemma	total	jan	feb	mar	apr	may	jun	jul	mean
1	coronavirus	1849	55	252	378	456	344	194	170	264.14
2	covid-19	1583	0	37	190	430	409	300	217	226.14
3	suisse	1503	37	96	249	424	381	158	158	214.71
4	pays	1442	21	182	176	360	320	231	152	206.0
5	cas	1338	30	197	222	271	195	250	173	191.14
6	crise	1127	12	24	143	364	310	185	89	161.0
7	pandémie	1102	0	35	114	335	286	195	137	157.43
8	personne	1087	13	108	180	337	187	145	117	155.29
9	santé	1083	19	104	211	243	252	155	99	154.71
10	virus	1004	28	128	175	208	195	140	130	143.43
11	épidémie	986	36	217	235	189	155	79	75	140.86
12	oms	934	36	141	145	220	151	114	127	133.43
13	temps	916	8	33	158	273	226	135	83	130.86
14	faire	883	8	41	160	226	195	147	106	126.14
15	monde	857	11	95	116	204	196	146	89	122.43
16	mesure	847	7	70	155	244	202	107	62	121.0

17	devoir	788	12	72	116	213	164	140	71	112.57
18	jour	765	11	65	135	199	152	137	66	109.29
19	mettre	722	11	44	130	187	159	115	76	103.14
20	nouveau	708	9	102	75	144	150	161	67	101.14

Table 7, 20 most frequent lemmas in French

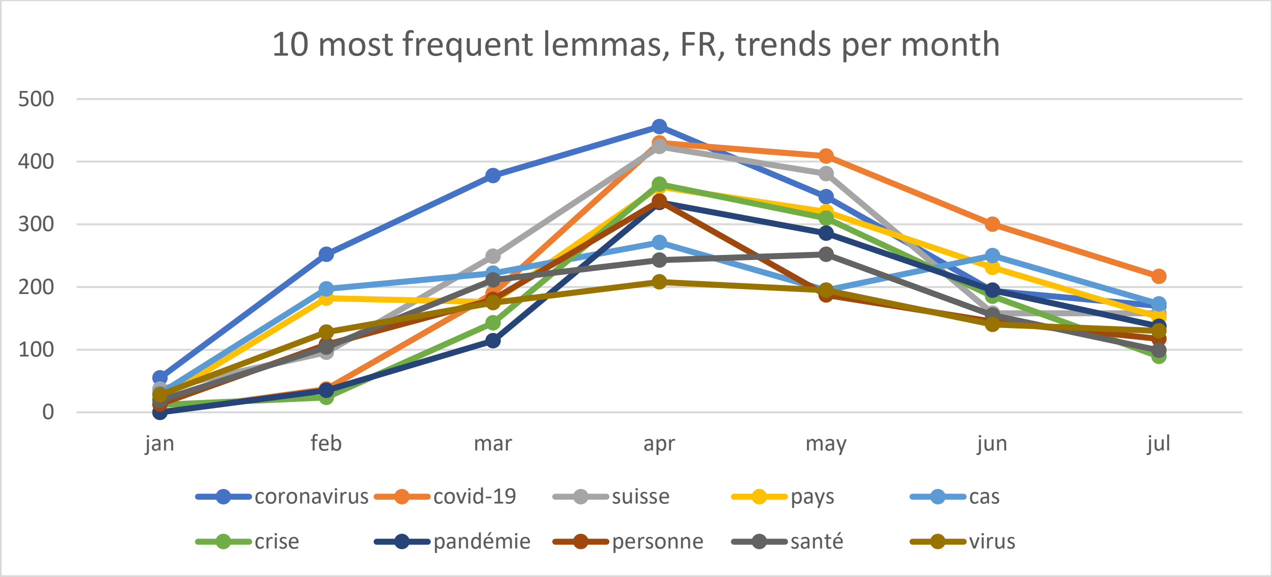

Figure 7, monthly trends of the 10 most common lemmas, French

#	lemma	total	jan	feb	mar	apr	may	jun	jul	mean
1	coronavirus	1818	160	358	730	330	90	60	90	259.71
2	caso	1434	104	240	704	254	34	52	46	204.86
3	oms	1048	64	100	164	332	180	138	70	149.71
4	cina	872	152	218	176	156	78	56	36	124.57
5	virus	728	156	120	172	118	54	62	46	104.0
6	contagiare	664	64	186	282	98	8	14	12	94.86
7	italia	650	30	254	258	28	16	14	50	92.86
8	contagio	604	12	94	308	112	12	34	32	86.29
9	morto	592	26	72	282	136	28	12	36	84.57
10	epidemia	558	82	132	198	86	12	22	26	79.71
11	sanitario	542	64	110	150	144	26	30	18	77.43
12	nuovo	522	22	80	244	110	10	32	24	74.57
13	emergenza	508	64	70	206	88	32	30	18	72.57
14	pandemia	488	2	18	138	134	82	46	68	69.71
15	covid-19	484	0	58	160	122	56	38	50	69.14
16	numerare	472	28	62	230	78	24	20	30	67.43
17	registrare	462	26	58	206	102	16	18	36	66.0
18	potere	450	24	54	158	130	38	24	22	64.29
19	settimana	442	26	104	170	84	14	24	20	63.14

20	sanità	426	42	82	138	70	34	24	36	60.86

Table 8, 20 most frequent lemmas in Italian

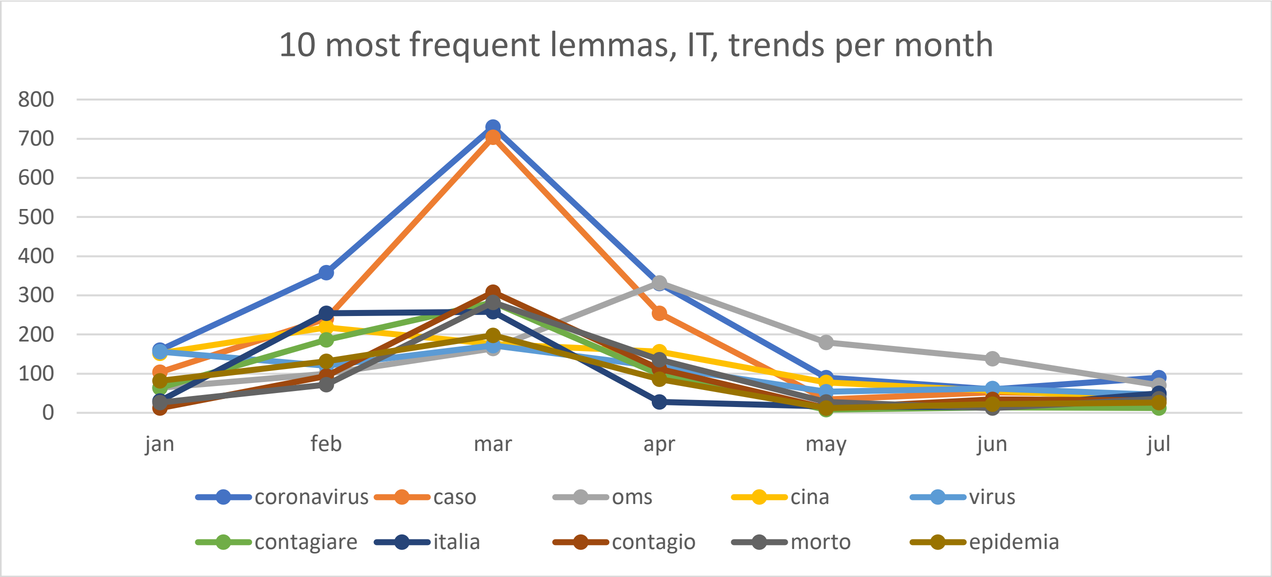

Figure 8, monthly trends of the 10 most common lemmas, Italian

#	lemma	total	jan	feb	mar	apr	may	jun	jul	mean
1	say	10024	511	1183	2293	1948	1336	1525	1228	1432.0
2	coronavirus	5696	246	634	1667	1197	596	902	454	813.71
3	2020	5388	110	169	713	1457	908	823	1208	769.71
4	covid-19	4452	0	102	657	1165	811	764	953	636.0
5	million	3937	32	129	538	981	720	608	929	562.43
6	year	3875	127	249	555	947	600	417	980	553.57
7	country	3755	125	330	858	786	567	557	532	536.43
8	people	3629	96	380	828	765	505	537	518	518.43
9	health	3620	129	409	715	753	588	525	501	517.14
10	new	3581	152	287	694	671	433	762	582	511.57
11	company	3507	70	194	656	959	486	448	694	501.0
12	case	3136	113	505	725	443	288	804	258	448.0
13	pandemic	2841	7	53	453	774	509	484	561	405.86
14	report	2722	77	237	465	589	297	594	463	388.86
15	virus	2699	174	490	590	431	378	311	325	385.57
16	swiss	2626	57	139	657	666	397	379	331	375.14
17	group	2594	31	96	422	764	340	367	574	370.57
18	include	2582	69	173	452	651	448	300	489	368.86
19	market	2579	135	209	518	593	259	373	492	368.43
20	world	2476	104	247	474	562	403	289	397	353.71

Table 9, 20 most frequent lemmas in English

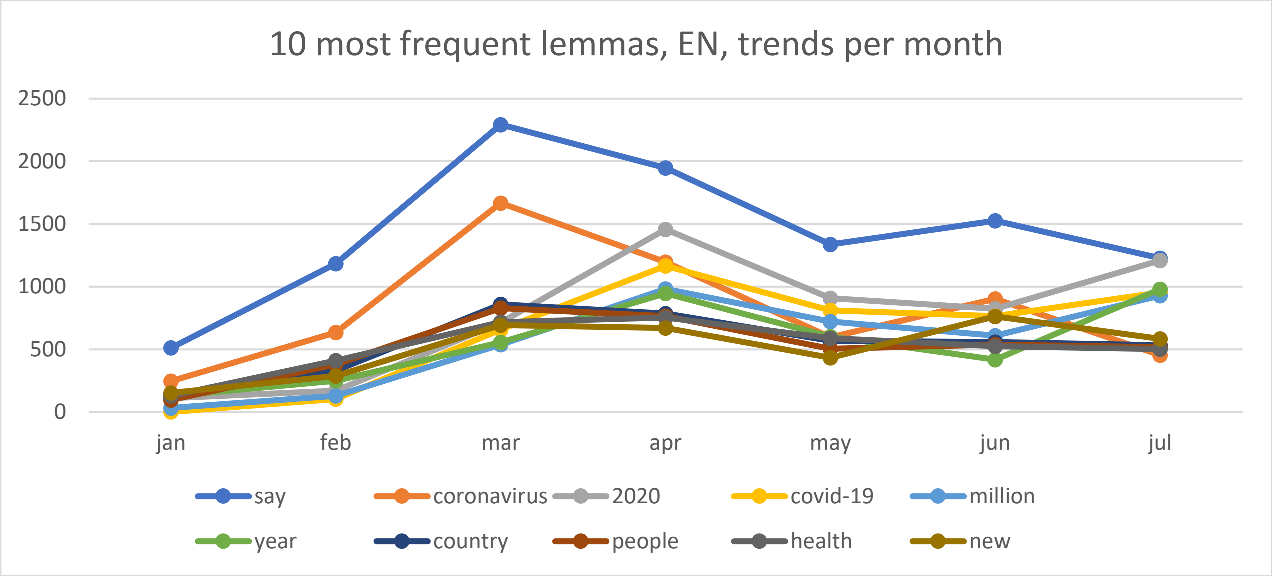

Figure 9, monthly trends of the 10 most common lemmas, English

The analysis of German lemmas, compared to the other linguistic subcorpora, indicates a public discourse highly focused on quantitative aspects of the pandemic ("prozent", "million", "milliarde", "zahl", "fall").

The French subcorpus indicates a public discourse focused on describing the pandemic and its effects on people ("cas", "crise", "pandémie", "personne", "santé"). It is rather interesting to notice the opposed trends of "pandemie" and "epidemie": the first increases by time, while the second decreases, with the swap point happening between march and april.

The Italian subcorpus appears to be focused on cases and fatalities more than the other ones ("caso", "contagiare", "contagio", "morto"). Interestingly, it is also the subcorpus in which "oms" (Italian acronym for "Organizzazione Mondiale della Sanità", i.e. WHO) ranks higher, indicating a higher attention for official WHO news and/or reports. The Italian subcorpus is also the only one in which "China" (i.e: "Cina") appears in the top 20 lemmas.

The English subcorpus, finally, seems dominated by information reported from other sources ("say"), which makes sense, given the fact that English is not an official language of the Confederation. Under the surface of lemmas not that different from those found in the other subcorpora (so, effects of the pandemic, quantitative information, information from official bodies) it is possible to notice many lemmas like "company", "group", "market", suggesting a higher attention to the economic and financial impact of the pandemic.

It appears that all the subcorpora provide, at varying levels, the following macro-categories of information:

- georeferenced information (information specific to countries, Cantons or cities);
- general information about the pandemic and about the virus;
- reports from authorities and official bodies;
- quantitative information.

Entities

Named Entity Recognition (NER) is another, more refined technique employed in text mining to conflate texts. It is widely employed in information extraction and retrieval, automatic summarization, automatic question answering and similar tasks (Nadeau and Sekine 2007; Kaur and Gupta 2010). Importantly, NER can recognize the category (e.g. person, location, organization, …) of a given word, allowing to define subsets of concepts in the corpus, making it possible to understand, for example, what person or what organization is mentioned more often. In the context of this project, information extraction by means of NER serves the purpose of validating what emerged with the analysis of lemmas, allowing in the meantime to gather more fine-grained information.

Moreover, SpaCy allows the definition of custom rules via regex syntaxis; in this context this feature has been experimentally used to define specific rules for “COVID-19” (a category comprising the virus or the disease it causes) and for “COVID19-r” (racially laden references to the virus or to the disease it causes, e.g. “the Chinese virus”). For more information on the definition of these rules, see the comments to the code contained in the Zenodo repository (Spitale, Merten, and Biller-Andorno 2020a).

Results are displayed in Tables 10, 11, 12, and 13 (entity, category, total count, monthly trend and mean for the 20 top entities in German, French, Italian and English), and in figures 9, 10, 11 and 12 (monthly trends of the 10 most frequent entities). As above, results are available for replication and for further analysis (Spitale, Merten, and Biller-Andorno 2020b).

The category scheme for German, French and Italian is based on the WikiGold standard (Balasuriya et al. 2009) and includes the following:

MISC=miscellaneous, ORG=organization, PER=person, LOC= place.

The category scheme for English entities is trained on OntoNotes Release 5.0 (Weischedel, Ralph et al. 2013) and is a bit more refined. It includes the following:

CARDINAL=Numerals that do not fall under another type, DATE=Absolute or relative dates or periods, EVENT=Named hurricanes, battles, wars, sports events, etc., FAC=Buildings, airports, highways, bridges, etc., GPE=Countries, cities, states, LANGUAGE=Any named language, LAW=Named documents made into laws, LOC=Non-GPE locations, mountain ranges, bodies of water, MONEY=Monetary values, including unit, NORP= Nationalities or religious or political groups, ORDINAL=ordinal numbers such as “first”, “second”, etc., ORG=Companies, agencies, institutions, etc., PERCENT=Percentage, including ”%”, PERSON=People, including fictional, PRODUCT=Objects, vehicles, foods, etc. (Not services), QUANTITY=Measurements, as of weight or distance, TIME=Times smaller than a day, WORK_OF_ART=Titles of books, songs, etc. (spaCy 2020a)

#	entity	cat.	total	jan	feb	mar	apr	may	jun	jul	mean
1	Coronavirus	MISC	4855	219	741	1842	842	626	273	312	693.57
2	Schweiz	LOC	4442	166	262	1352	825	736	559	542	634.57
3	Schweizer	MISC	3193	64	245	825	641	494	379	545	456.14
4	Virus	MISC	2832	138	492	977	493	337	163	232	404.57
5	Deutschland	LOC	2038	46	147	674	373	439	207	152	291.14
6	China	LOC	1985	220	522	459	306	265	81	132	283.57
7	Corona-Krise	MISC	1696	4	5	400	436	463	148	240	242.29
8	Zürich	LOC	1562	35	67	233	359	414	115	339	223.14
9	Italien	LOC	1419	8	241	638	260	128	97	47	202.71
10	Coronavirus	COVID19	1394	86	218	444	295	174	103	74	199.14
11	BAG	ORG	1383	119	109	442	216	166	132	199	197.57
12	der Schweiz	LOC	1247	27	84	427	222	216	122	149	178.14
13	Covid-19	MISC	1246	6	52	268	294	300	139	187	178.0
14	Bern	LOC	1234	28	53	239	205	294	227	188	176.29
15	Europa	LOC	1115	18	123	291	215	262	93	113	159.29
16	Frankreich	LOC	870	13	40	276	174	209	88	70	124.29
17	Quarantäne	MISC	830	26	111	251	79	97	73	193	118.57

18	USA	LOC	813	16	74	136	176	200	76	135	116.14
19	Österreich	LOC	720	4	40	259	95	173	80	69	102.86
20	Corona-Krise	LOC	704	4	5	139	220	179	59	98	100.57

Table 10, 20 most frequent named entities in German

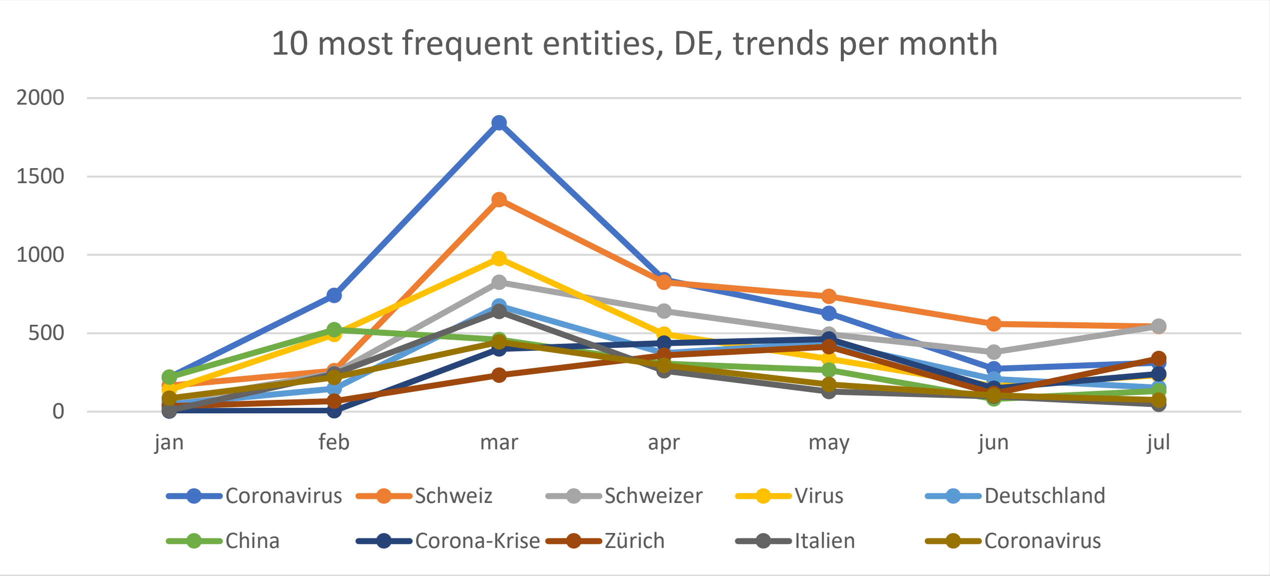

Figure 10, monthly trends of the 10 most common entities, German

#	entity	cat.	total	jan	feb	mar	apr	may	jun	jul	mean
1	coronavirus	COVID19	1621	51	220	326	400	304	171	149	231.57
2	Covid-19	MISC	1325	0	31	171	349	339	261	174	189.29
3	OMS	ORG	1082	44	171	165	254	173	130	145	154.57
4	Suisse	LOC	851	23	52	143	244	204	93	92	121.57
5	Chine	LOC	450	40	155	30	92	63	34	36	64.29
6	Etats-Unis	LOC	325	8	19	29	132	52	53	32	46.43
7	Genève	LOC	287	4	41	55	65	78	24	20	41.0
8	Conseil fédéral	ORG	238	0	2	35	70	62	51	18	34.0
9	Europe	LOC	210	3	28	20	75	32	39	13	30.0
10	Le Temps	ORG	202	3	7	40	56	42	31	23	28.86
11	la Chine	LOC	185	10	41	35	38	27	20	14	26.43
12	Italie	LOC	184	0	36	51	41	27	22	7	26.29

13	France	LOC	183	2	32	27	55	31	20	16	26.14
14	Organisation mondiale de la santé	ORG	174	4	28	31	38	28	25	20	24.86
15	Etats	LOC	160	0	21	32	41	29	17	20	22.86
16	Wuhan	LOC	151	16	54	10	31	21	8	11	21.57
17	SARS	MISC	144	0	0	37	51	20	13	23	20.57
18	CoV-2	MISC	141	0	0	35	48	22	14	22	20.14
19	OFSP	ORG	132	10	1	34	32	29	17	9	18.86
20	Allemagne	LOC	130	3	11	22	39	23	18	14	18.57

Table 11, 20 most frequent named entities in French

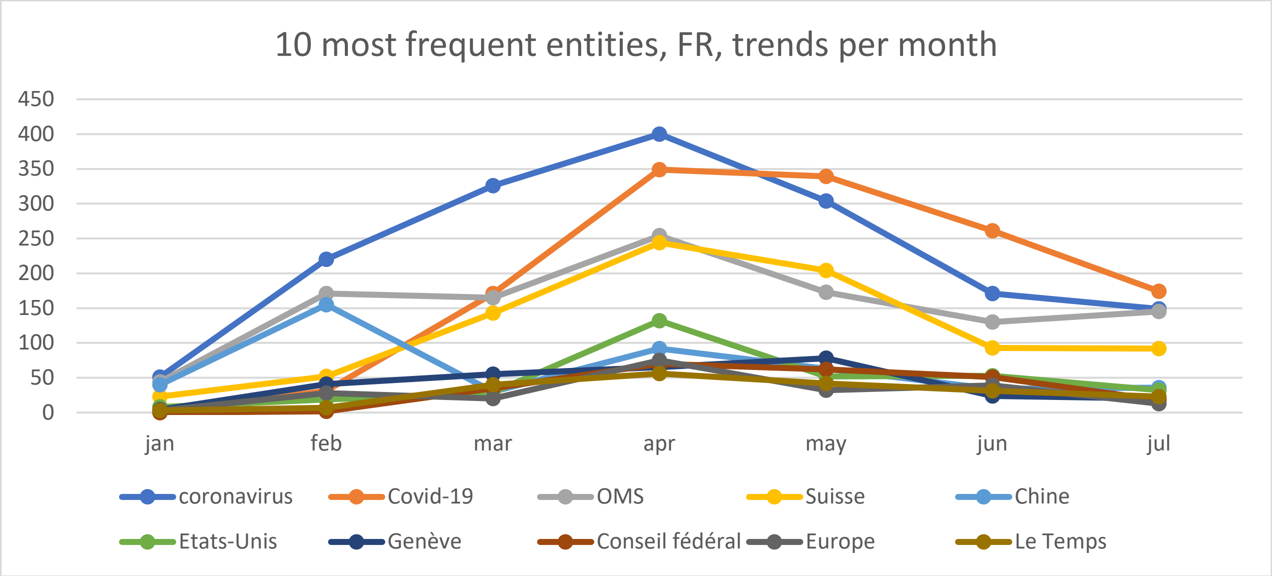

Figure 11, monthly trends of the 10 most common entities, French

#	entity	cat.	total	jan	feb	mar	apr	may	jun	jul	mean
1	coronavirus	COVID19	1412	138	282	574	260	62	42	54	201.71
2	Oms	ORG	882	50	74	128	288	154	124	64	126.0
3	Cina	LOC	854	144	212	176	154	76	56	36	122.0
4	Italia	LOC	598	30	238	234	26	12	14	44	85.43
5	Paese	LOC	536	12	66	296	98	30	8	26	76.57
6	Covid-19	MISC	402	0	46	142	108	30	36	40	57.43
7	Paesi	LOC	302	14	30	116	56	30	36	20	43.14
8	Coronavirus	MISC	300	16	58	104	60	22	16	24	42.86
9	Usa	LOC	298	22	22	92	96	28	22	16	42.57
10	Europa	LOC	298	22	38	126	52	12	32	16	42.57
11	Germania	LOC	284	8	44	166	40	10	4	12	40.57

12	Svizzera	LOC	250	2	56	84	54	26	18	10	35.71
13	Stati Uniti	LOC	246	14	18	82	72	30	8	22	35.14
14	Pechino	LOC	244	40	54	12	50	36	46	6	34.86
15	Spagna	LOC	230	0	42	142	40	2	2	2	32.86
16	Wuhan	LOC	224	110	42	20	20	12	20	0	32.0
17	Iran	LOC	212	2	76	120	12	2	0	0	30.29
18	Francia	LOC	192	8	48	100	16	12	4	4	27.43
19	Corea del Sud	LOC	172	16	58	66	22	4	0	6	24.57
20	Trump	MISC	170	0	2	22	120	14	12	0	24.29

Table 12, 20 most frequent named entities in Italian

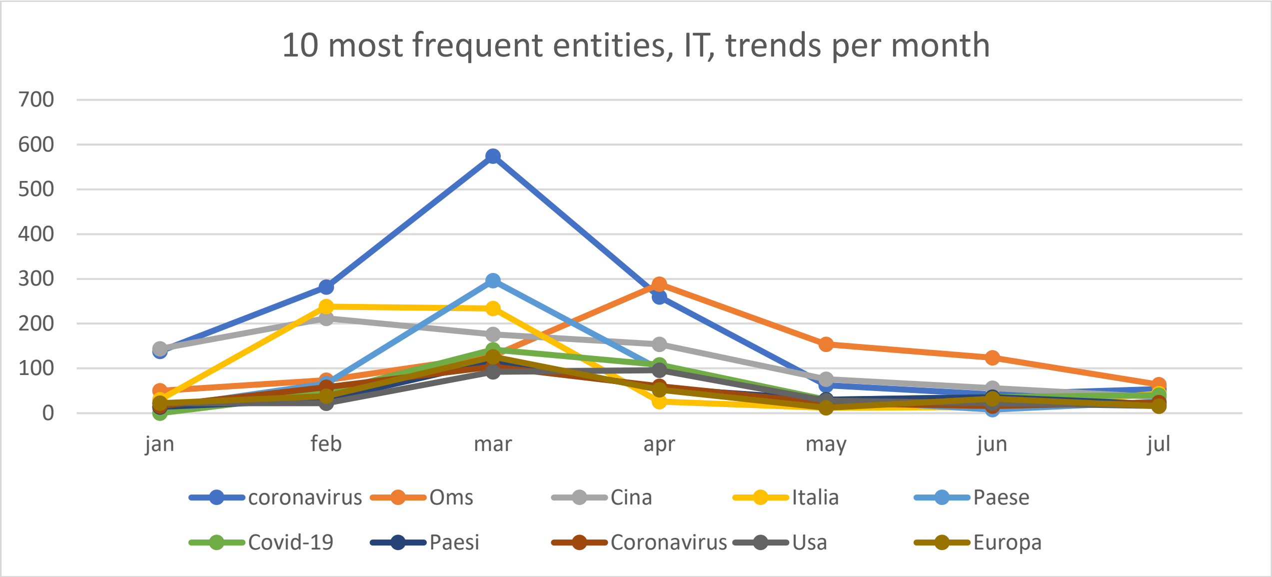

Figure 12, monthly trends of the 10 most common entities, Italian

#	entity	cat.	total	jan	feb	mar	apr	may	jun	jul	mean
1	coronavirus	COVID19	5227	205	584	1525	1105	556	841	411	746.71
2	China	GPE	1982	277	408	315	455	215	144	168	283.14
3	Switzerland	GPE	1965	34	153	519	476	292	255	236	280.71
4	Swiss	NORP	1490	38	94	404	369	214	205	166	212.86
5	first	ORDINAL	1218	36	174	219	234	177	156	222	174.0
6	US	GPE	1103	60	43	140	298	222	141	199	157.57
7	2020	DATE	1088	38	48	142	328	148	122	262	155.43

8	Italy	GPE	978	16	269	401	165	34	61	32	139.71
9	Covid-19	COVID19	973	0	39	111	224	116	295	188	139.0
10	one	CARDINAL	904	24	66	156	193	171	111	183	129.14
11	2019	DATE	886	15	43	136	281	109	88	214	126.57
12	U.S.	GPE	884	64	74	217	218	103	101	107	126.29
13	Europe	LOC	860	16	86	249	186	91	62	170	122.86
14	Germany	GPE	802	22	56	231	175	98	120	100	114.57
15	WHO	ORG	728	15	48	62	277	207	55	64	104.0
16	Geneva	GPE	610	14	126	113	113	110	75	59	87.14
17	UK	GPE	578	27	45	155	121	93	93	44	82.57
18	two	CARDINAL	561	24	56	117	79	88	115	82	80.14
19	Thursday	DATE	557	46	86	166	81	46	74	58	79.57
20	France	GPE	548	17	64	206	121	50	56	34	78.29

Table 13, 20 most frequent named entities in English

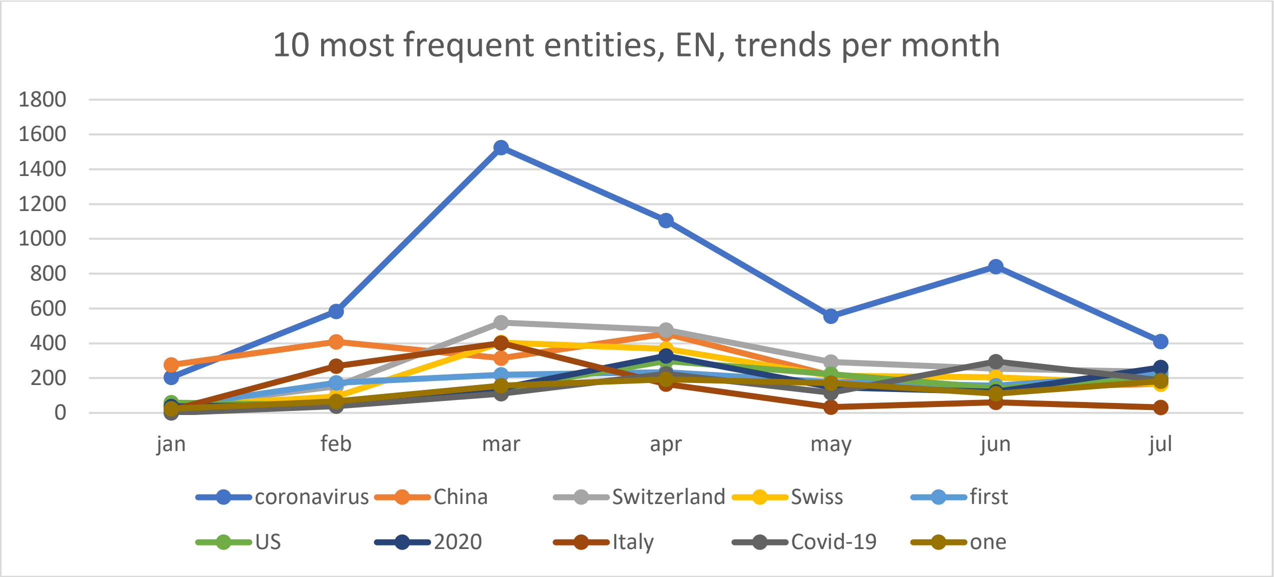

Figure 13, monthly trends of the 10 most common entities, English

The most frequent category of named entities in the German subcorpus is LOC, i.e. geographical places. This information allows to contextualize and expand what emerged in the lemma analysis: German media reported lots of quantitative information referred to "Schweiz", "Deutschland", "China", "Italien", "Frankreich", "Österreich", "USA" and so on.

Importantly, the most named countries are either the neighboring ones or the ones in which the pandemic it more strongly. The only cities that appear in the top 20 entities are Zurich and Bern. "BAG", the acronym of "Bundesamt für Gesundheit" (i.e: Federal Office for Public Health) is the first organization mentioned, signifying a special attention to reports, news and deliberation of the Swiss federal body in charge of public health.

The analysis of the French named entities represents a similar situation, with lots of mentions of Countries that are either neighboring or hit severely by the pandemic ("Suisse", "Chine", "Etats-Unis", "Europe", "Italie", "France"). The first organization mentioned is "OMS" (French acronym for "Organisation mondiale de la santé", i.e. WHO), followed by "Conseil fédéral" (i.e. Federal Council) and by "OFSP" (French acronym for "Office fédéral de la santé publique", i.e: Federal Office for Public Health). The only cities that appear in the top 20 entities are Genève and Wuhan.

Also the Italian named entities go in the same direction: the most mentioned Countries are "Cina", "Italia", "Usa", "Europa", "Germania", "Svizzera", "Stati Uniti", "Spagna", "Iran", "Francia" and "Corea del Sud". "OMS" (Italian acronym for "Organizzazione Mondiale della Sanità", i.e. WHO) is the second most frequent entity, after "coronavirus". The only cities that appear in the top 20 entities are "Pechino" and Wuhan.

The English named entities follow an almost identical pattern: nearby Countries or Countries with significant outbreaks ("China", "US", "Italy", "Europe", "Germany", "UK"), the WHO, Geneva.

NIH BSSR Collection

On the 14th of May 2020 the NIH Office of Behavioral and Social Sciences released a document listing "data collection instruments, including surveys, for assessing COVID-19-relevant Behavioral and Social Science (BSSR) domains for clinical or population research" (NIH Office of Behavioral and Social Sciences Research (OBSSR) 2020).

In order to understand what are the foci of current BSSR research related to COVID-19 we screened all the items of every survey in the NIH collection, classifying the topic of each one of the subscales and then grouping them in categories. We identified 6 main categories and 35 subcategories, divided as follows:

- Financial impact: Impacts on work & childcare; Deprivation
- Social practices: Social connections; Social distancing; Social capital

- Behavioral dispositions: Recent risky/protective behavior behavior; Cleaning behavior; Work behavior; Coping behavior; Interpersonal conflict; Comparison with others; Anticipated vaccination behavior; Healthful behavior; Sleep; General disruptions
- Moral preferences: Willingness to distance; Federal government response; State government response; City government response
- Emotional state: Depression Screening; Anxiety Screening; Stress Scale Resilience; Emotional Regulation; Loneliness; General Emotional Impact; Worries; Obsession with Covid; General Well-being; Cognitive Well-being; Sleep
- Cognitive understanding: COVID-19 symptoms; What to do if symptomatic; COVID-19 Transmission; Self-protection.

This work allowed us not only to have a comprehensive overview of what's going on in the field in order to align our interest (or to direct it better in some cases), but more importantly to have a solid basis to start with for defining our own survey tool.

In the following section we outline the content of the survey, the sources (when existing), the scoring scheme, the rationale and a summary of the information to provide.

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PubliCo: a convenient decalogue for writing the informational text

UNPUBLISHED MATERIAL.

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Providing informative content implies – surprise! – writing informative content. Providing personalized informative content implies writing several versions of the same content, with varying levels of complexity and detail, depending on who that information is tailored for. There are several factors to keep in mind when preparing the informative content to feed back to the users in PubliCo. This document tries to condense the most important ones in a decalogue useful for planning, verification, and evaluation. A practical example (based on the PubliCo Core Survey v1) is provided.

1. Take off the researcher's hat – the focus is providing information. The information feedback is not a nice to have, a fancy optional for the survey, it's a core component of the system. If the information is good, timely, and useful, people will use the system and

provide valuable data for closing the loop. That is the point: writing the information feedback is not a chore, nor an exercise of style.

2. Go back to what we know and start from there: what kind of information do people need? What kind of information is available? This task can be supported by the use of the tools described in the previous section – Factiva NLP analysis and google trend analysis. When you identify a gap, prepare an information package, and then challenge it. Ask yourself: is it needed? Is it relevant? Is it precise? Is it clear?

3. Mind the segmentation! What factors are known to determine the understanding or the perceived relevance of this information? Demographics? Cognitive understanding? And what factors might play a role? Plan your rules accordingly, and define meaningful score brackets.

4. Keep it simple. It does not have to be a full essay addressing every relevant aspect of a topic, but quick and usable information, understandable also for a lay audience. We don't build walls of text.

5. Acknowledge uncertainty! Especially in the context of a new event, it is fine and honest to say: 'we don't know yet' or 'for the time being' or 'as far as we know'. Stress the fact that this information is written based on the best evidence which is currently available, but that evidence can and will change over time.

6. Never be judgemental and avoid comparative language. It's possible (and advisable) to provide correct information to people without bashing them for what they believe or for what they don't know. Especially on morally relevant topics: we know what people believe, but we don't know why. An educational attitude works much better than bashing someone for their ignorance. And take care of the language: 'people with special needs' works much better than 'handicapped people', and 'people dubious about the efficacy of vaccines' works much better than 'those damn antivaxxers'.

7. Reflect on your own bias when preparing the information: what seems simple or obvious to you could be perceived in a completely different way by the users. Try to understand how people will understand your text, and pilot-test it if possible. Hope for the best, plan for the worst.

8. Be creative – include bullet points, lists, images, or even embeds (e.g: videos) if you think that these can help delivery the message faster or easier. Again, it's not an exercise of style or a show-off: if it helps, use it.

9. Provide sources, as much as possible in national languages. People might be willing to dig deeper and we can point them to good starting points. Even complot theorists like to think that they are doing their own research, and using their own critical thinking skills. Capitalize on this inclination, and give people something to explore, if they wish so. It could be information based on scientific evidence and prepared by official sources (e.g: BAG, WHO). When willing to provide scientific studies, rather than linking to single papers, link to PubMed queries. It's a way to ensure that we provide a comprehensive and updated overview on a topic.

10. Finally, provide resources when relevant, e.g: contacts to associations or organizations for psychological health. You are writing informative feedback on access to vaccinations? Provide the contacts of the vaccination centers. Something about border crossing?

A practical example: cognitive understanding

Question

What are five of the main symptoms people infected with COVID-19 may experience?

Question type: checkbox, randomized order, validation logic allows max. 5 choices.

Choices

1. 2|Sore throat
2. 2|Cough (usually dry)
3. 2|Shortness of breath
4. 1|Chest pain
5. 2|High temperature
6. 1|Sudden loss of sense of smell and/or taste
7. 1|Headache
8. 2|General weakness, feeling unwell

9. 1|Aching muscles

10. 1|Nausea

11. 0|Hair loss

12. 0|Dry skin

13. 0|Mouth ulcers

14. 0|Red, brown, pink, or purplish blotches on or under the skin or inside the mouth, nose, or eyelids

15. 0|Rapid weight loss

Scoring

Items 1-5 are the five main symptoms (2 points). Items 6-10 are secondary symptoms (1 point). Items 11-15 are not symptoms of COVID-19 (0 points).

The participant selects max 5 choices.

Range: 0-10.

Informative content

Score range	Informative content
0-3	COVID-19 is a tricky disease, but its symptoms are known and easy to identify. The most common ones are respiratory: sore throat, cough (usually dry), shortness of breath, and general weakness, often accompanied by high temperature and sudden loss of sense of smell and/or taste. You can find out more on COVID-19 symptoms on the [dedicated BAG website](https://www.bag.admin.ch/bag/en/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/krankheit-symptome-behandlung-ursprung.html#1145977831).
4-6	Looks like you know some of the main symptoms of COVID-19. Good! The most common symptoms of COVID-19 are sore throat, cough (usually dry), shortness of breath, general weakness, and high temperature. Some of the less common symptoms include sudden loss of sense of smell and/or taste, headache, chest pain, aching muscles and nausea.

	Keep in mind: the incubation period of COVID-19 is generally five days, up to a maximum of 14 days. You can find out more on COVID-19 symptoms on the [dedicated BAG website](https://www.bag.admin.ch/bag/en/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/krankheit-symptome-behandlung-ursprung.html#1145977831).
7-10	Great, looks like you know the main signs of COVID-19 really well. But did you know that there are some less frequent symptoms? The most common symptoms of COVID-19 are sore throat, cough (usually dry), shortness of breath, general weakness, and high temperature. Some of the less common symptoms include sudden loss of sense of smell and/or taste, headache, chest pain, aching muscles and nausea. Keep in mind: the incubation period of COVID-19 is generally five days, up to a maximum of 14 days. You can find out more on COVID-19 symptoms in the [dedicated BAG website](https://www.bag.admin.ch/bag/en/home/krankheiten/ausbrueche-epidemien-pandemien/aktuelle-ausbrueche-epidemien/novel-cov/krankheit-symptome-behandlung-ursprung.html#1145977831).. If you want to learn more, you can find some scientific literature on the symptoms of COVID-19 [here](https://pubmed.ncbi.nlm.nih.gov/?term=%28%22covid-19%22+or+%22covid+19%22+or+%22sars+cov-2%22%29and+%28%22symptoms%22+or+%22clinical+diagnosis%22%29&filter=pubt.meta-analysis&filter=pubt.systematicreview).

6. Passive social listening

Chapter 6 is the result of a 'Friday project' – in normal times, far away from impending deadlines and last rushes to finish something big and important (ehm…) I had this agreement with my supervisor: on Fridays I play – with new ideas, new methods, new topics. On the one hand, it is a way to keep yourself intellectually alive; on the other, it is a strategy to identify new areas of potential research interest. It is a valuable and clever way to foster and pursue creativity and innovation, for which I am very, very thankful (and which I could not recommend strongly enough to whoever is in the position of making such concessions to their employees). When COVID-19 vaccination certificates started to roll out, I noticed an increasing agitation among no-vax digital communities, worried about their privacy, their rights, and their possibility to keep conducting a normal life – without getting vaccinated. Some were just trying to obtain or to forge fake certificates, some were organizing rallies and protests, arguing a lot about their reasons. The study presented in Chapter 6 is a first of its kind: adopting a combination of NLP and qualitative methods, we mapped and analysed the content of online discourse on vaccines, freedom, and covid passes. It is a robust method for social listening – passive social listening, to be more precise, that comes with several strengths, but also relevant ethical implications.

Concerns Around Opposition to the Green Pass in Italy: Social Listening Analysis by Using a Mixed Methods Approach

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Abstract

Background

The recent introduction of COVID-19 certificates in several countries, including the introduction of a European Green Pass, has been met with protests and concerns by a fraction of the population. In Italy, the Green Pass has been used as a nudging measure to incentivize vaccinations, since unvaccinated people are not allowed to enter restaurants and bars, museums, or stadiums.

Objective

This study aims to understand and describe the concerns of anti-green pass individuals in Italy, the main arguments of discussion, and their characterization.

Methods

We collected data from Telegram chats and analysed with a mixed-methods approach the arguments and the concerns that were raised by the users.

Results

Most individuals opposing the green pass share anti-vaccine views, but that doubts and concerns about vaccines are not often among the arguments raised to oppose the green pass. Instead, the discussion revolves around legal aspects and the definition of personal freedom. Further, we explain the nature of the dichotomy and similarity between anti-vaccine and anti-green pass discourse, and we discuss the ethical ramifications of our research, focusing on the use of Telegram chats as social listening tool for public health.

Conclusion

A large fraction of anti-green pass individuals share anti-vaccine views. We suggest public health and political institutions to provide a legal explanation and a context for the use of the green pass, as well as to continue focusing on vaccine communication to inform hesitant individuals. Further work is needed to define a consensual ethical framework for social listening for public health.

Keywords

Green pass, COVID-19, vaccine, freedom, social listening, bioethics, telegram

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Introduction

Background

Since the beginning of large-scale vaccination campaigns against COVID-19, many countries had to deal with the issue of vaccine hesitancy (Wouters et al. 2021). Already defined by the WHO in 2019 as one of the major threats to global health (WHO 2019), vaccine hesitancy has become even more relevant in the context of the current pandemic (Germani and Biller-Andorno 2021a). In Israel, the first country able to ensure sufficient supplies of the Pfizer – BioNtech vaccine, the Ministry of Health swiftly started a vaccination campaign in late 2020. However, after covering health care staff, elderly and vulnerable patients, the campaign reached a stagnation phase, due to a relevant percentage of individuals not willing to get vaccinated. After considering other forms of incentives (Saban et al. 2021), the Israeli Ministry of health developed a new ad hoc strategy to increase vaccination rate. According to this plan, vaccinated people would receive a special document which allows them access to social and cultural events, national and international mobility, and exemption from quarantine. The declared aim of this document, or "green passport", was to encourage citizens to receive COVID-19 vaccinations while allowing some reopening of the economy (Wilf-Miron, Myers, and Saban 2021). The proposal for the Israeli green passport was passed on the 14th of December 2020 (Saban et al. 2021); on the 27th of January 2021, the eHealth network of the European Commission started to develop a set of guidelines in order to implement a "COVID-19 green pass" system in Europe. On the 1st of June 2021 the EU Gateway, i.e. the backbone interconnecting national green pass systems in the European Union, went live (European Commission 2021).

When compared with other nudging strategies to tackle vaccine hesitancy, the green pass looks like a promising concept, as it gives incentives to people to get vaccinated without imposing a decision; however, already in its first implementation in Israel, it generated some debate as it can be considered as a tool for discrimination based on someone's vaccination status. Another argument often used by green pass critics regards privacy: when showing their green pass, people are de facto obliged to disclose health information – thus sensitive information – to third parties (Wilf-Miron, Myers, and Saban 2021).

The adoption of the green pass strategy in Europe caused the very same debate and the very same arguments already seen in Israel. But debates need a stage to happen, and in a time of physical distancing due to containment measures, many of these discussions have been taking place online, on social media and communication platforms. As popular social media platforms increasingly corrected their policies to decrease the flow of misinformation (Kang-Xing 2020; Twitter inc. 2021), people and organizations holding critical views about the green pass started to deplatform towards alternative social media channels, a phenomenon already seen and studied, mostly regarding the far-right and conservative world (Rogers 2020). Notably, one of the most prominent destinations for deplatformed individuals and organizations has been Telegram.

Over the last years, Telegram has become one of the most prominent instant messaging services. This success is due to a combination of two factors: on the one hand, end-to-end encryption (Jakobsen 2015) and an infrastructure distributed over several jurisdictions (Telegram 2021) makes it rather difficult to extract data from the system (Urman and Katz 2020). As stated on the official Telegram's FAQ, to this day Telegram has "disclosed 0 bytes of user data to third parties, including governments" (Telegram 2021). On the other hand, Telegram's services go way beyond conventional instant messaging services: Telegram groups allow a maximum of 200.000 members and include advanced features like unified history, instant search, replies, permissions and moderation tools, making them outstanding tools for many-to-many discussions. In parallel, Telegram broadcast channels allow an unlimited number of followers, making them an appealing alternative to Twitter for one-to-many communication (Telegram 2021; Dargahi Nobari et al. 2021). This combination of publicity, mobilization capabilities, and privacy provides a solution to the so-called "terrorists' dilemma", i.e. the balancing security and outreach in choosing an online communication platform (Shapiro 2013).

The use of Telegram among no-green-pass groups in Italy started to grow rapidly already in July 2021: as soon as the green pass was introduced, groups and individuals offering forged green passes for purchase started to exist (AGI 2021), as well as groups organizing protests and rallies against the green pass (Rossi 2021).

Aims

This study has a double aim: 1) to study the discourse revolving around the opposition to the green pass and its use in Telegram chats by no-green-pass groups in Italy, with a focus on groups used by university students; 2) to detail a novel approach to online social listening using a combination of quantitative and qualitative approaches, and to question its ethical aspects.

Methods

Ethical and legal considerations

As this study does not fall under the scope of the Swiss Human Research Act (The Swiss Federal Council 2014), an authorization from the Cantonal Ethics Committee is not required. The messaged analysed in this study have been retrieved from public chats using the "download history" function of Telegram Desktop. This qualifies the data as "publicly available". According to the GDPR (*Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the Protection of Natural Persons with Regard to the Processing of Personal Data and on the Free Movement of Such Data, and Repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA Relevance)*, n.d.), art. 6.1, data processing without explicit consent of data subjects is possible when protecting the interest of the data subject and when "necessary for the performance of a task carried out in the public interest". Research falls in the category of public interest, but this criterion being very broad, it is important to weigh the public interest and benefits to the risk for the individuals, especially because the dataset might contain special categories of personal data (i.e. health, politics or world-view-related data). Generally, information detailed in art. 14 of the GDPR should be provided to the data subjects individually, although this could be considered as a disproportionate effort, given the number of users involved in this study. On the other hand, one could argue that the necessary information could be provided in a general way through posting into those chats. Since either way this transparency might result in both a higher risk of re-identification and a serious impairment to the pursue of research, it could be argued that is against the public interest and should therefore be omitted. Art. 14.5 and 89 of the GDPR exempt from the provision of information to study participants where and insofar it would involve a disproportionate effort or render impossible or seriously impair the achievement of the objectives (i.e. the research goals in the public interest). As specified in art. 14.5.b, we took appropriate measures to protect the privacy of data subjects whose messages are included in our study: the JSON files retrieved from Telegram have been completely anonymized (removal of personal names and toponyms from the message text) and pseudonymized (replacement of the user ID with a pseudonym); the original dataset has been destroyed; the analysis has been conducted on the anonymized version; the anonymized dataset will be available upon request; as the search of segments of text in the original chat would allow re-identification, the links to the chats will not be disclosed.

Data collection

Data were collected from two groups of chats. The first comprises no-green-pass groups of Italian universities (one in the north, one in the center, and one in the south) and generic no-green pass groups. The second, our negative control, comprises groups dedicated to the discussion of video games, parrot breeding, and other general topics. These chats were randomly selected among the Italian Telegram chat landscape, with the condition that the discussion would still be active and that at least 200 users joined the chat.

We identified relevant chats and downloaded the message history as a JSON file. We downloaded the JSON files containing the entire history of said groups on the 9th of September 2021. The data collection is described in Table 1.

Category	*Group description*	*n of users*	*n of messages*
no green pass	university, north	1770	7356
	university, center	**5168**	**10464**
	university, south	479	1879
	generic	**12295**	**33707**
	Total	19712	53406
control	parrots	296	48494
	videogames	**750**	**43322**
	generic	294	10588
	generic	**210**	**1453**
	generic	218	21611

	Total	1768	125468

Table 14. Data collection: composition of the groups, users, number of messages. The table lists the category to which the groups belong (no green pass or control); the description of the group, the number of users and the number of messages in the group.

Data were downloaded directly using the function "export chat history" of Telegram's official desktop client. For this study, we downloaded only textual data. We parsed the JSON files into Pandas data frames. To protect the privacy of the users while still maintaining the possibility to track conversations in qualitative analysis, we combined anonymization and pseudonymization. Anonymization was performed by removing metadata from messages, by removing personal names and replacing them with [name] **(de Sterlich 2017)**. Similarly, every toponym was replaced with [place] **(ISTAT 2021)**. Direct mentions of users in the text (e.g: @thisuser) were searched and replaced with [username]. Surnames were not removed from messages. Being the chat an informal context, people do not refer to other members of the chat or to themselves using surnames. However, surnames are often used to refer to public figures or sources of information, and thus represent a valuable component for the analysis.

Analysis

For this project we used a mixed methods approach, which involves the use of qualitative and quantitative data. For the quantitative analysis, with a top-down approach we defined a series of dictionaries relevant for the purpose of this study, each one containing regular expressions that belong to the same concept. Regex allows the definition of fairly complex rules, able to reduce ambiguity and capture precise concepts. As an example: the rule (tesser.\sverd.?|pass\sverd.?|certifica\w*\sverd.?) will fire on "tessera verde" (green pass) or "tessere verdi" (green passes) or "pass verde" (green pass) or "certificato verde" (green certificate), but not on "casa verde" (green house) or "verderame" (verdigris) or "tessera del cinema" (cinema card). The autocoding has a weight system: if only one rule from the dictionary fires, the autocode is assigned a weight of 1, if 2 rules fire, the weight will be 2 and so on. Autocodes can then be used to measure the prevalence of topics through the corpus, to segment the quantitative analyses, or as a starting point for the qualitative work. Third, we extracted the lemmas used in the corpus using the python package "Spacy" and its pre-trained model for Italian (ExplosionAI GmbH 2021). This is performed on a large bag of words including every message in the corpus and by dividing messages by code. In the final step of the quantitative analysis we performed a sentiment analysis (B. Liu 2012), both on the entire corpus and on messages divided by code. The sentiment analysis was performed using the python package "feel-it" (Bianchi, Nozza, and

Hovy 2021), through which we calculated the probability of positive or negative sentiment for each message. We developed the analysis pipeline in Python; the code is structured in a Jupyter Lab notebook, available through Zenodo (Spitale, Germani, and Biller-Andorno 2021).

For the qualitative analysis we generated a structured text file, annotated with pseudonymized speakers and codes resulting from the autocoding system. The file was then imported in MaxQDA for thematic analysis. The development of the regular expressions used for autocoding has been an iterative process. We ran the code several times, exploring the results, noting the gaps, and fine tuning the regular expressions. The thematic analysis has been conducted by native Italian speakers on messages written in Italian; the text has been translated by the authors to be comprehensible to a wider audience, but still as close as possible to the original. The original quotes in Italian are provided as supplementary material (appendix 2).

Results

Quantitative results

Lemmas, terms and rules: the no-green pass discourse encompasses legal aspects, actions and vaccine scepticism

To understand the interests of individuals critical of the green pass, their arguments and the opinions that shape their position in the debate, we quantified and analysed the most frequently used lemmas in control chats (**Table S2**) – with individuals not focusing their discussion on issues related to green pass, vaccines or COVID-19 – and in chats focused on green pass opposition (**Table S3**). As a positive control, we checked whether the lemmas “green” and “pass” were found to be among the most frequently used in green pass opposition chats when compared with control chats. As expected, “green” was the second most frequently used lemma in green pass opposition chats, and “pass” was the fourth most frequently used lemma (frequencies 9.2% and 7.5%, respectively). Instead, these lemmas were barely used in control chats (frequency of 0.02% for both lemmas). As expected, the average frequency of the two lemmas combined (“green” + “pass”) was significantly higher in green pass opposition chats in comparison with control chats (**Fig. 1A**). Among the 20 most used lemmas in either control or green pass opposition chats, we identified two relevant categories of terms: legal terms and action terms. Legal terms included law (*legge*) and article (*articolo*). These terms were highly overrepresented in green pass opposition chats when compared with control chats (Fig. 1B). Action lemmas included can (*potere*), must (*dovere*), want (*volere*), know (*sapere*), ask (*chiedere*), do (*fare*), say (*dire*), speak (*parlare*), take (*prendere*), put (*mettere*), use (*utilizzare*), come and go (*andare* and *venire*), write (*scrivere*). Among these, we identified three lemmas to be relevant and underrepresented in green pass opposition chats: Take (*prendere*), put (*mettere*) and use (*utilizzare*). Overrepresented lemmas were can (*potere*), ask (*chiedere*) and speak (*parlare*) (Fig. 1C). (Fig. 2). As expected, the rule for "green pass" fired very frequently in green pass opposition chats, and more frequently than the rules "COVID-19" and "Freedom". Surprisingly however, the rule "vaccine" was the most frequently used in green pass opposition chats, more so than the rule "Green Pass", indicating that among green pass critics, even when the discussion revolves around legal aspects connected to personal freedom, scepticism towards vaccines likely remains as the predominant reason to oppose the green pass.

"No green pass" individuals have a negative sentiment towards green pass and vaccines

After having identified the predominant themes associated with anti-green pass discourse, we analysed whether such discourse is associated with a higher probability of negative sentiment. By defining the likelihood of negative sentiment for each message, we averaged the sentiment for each chat and finally across chats within the same category. As expected, the average likelihood of negative sentiment was significantly higher in green pass opposition chats when compared with control chats, with a probability of 0.70 and 0.55, respectively (Fig, 3A). In addition, we calculated the average probability of negative sentiment associated with the rules "COVID-19", "Freedom", "Green Pass", "Vaccine", and determined that for all these rules, messages depicting negativity were overrepresented in green pass opposition chats when compared with control chats (Fig. 3B). This effect was significant for the rule "Green Pass", which can serve as a positive control indicating that green pass critics are, in fact, assessing the issue with negative sentiment, when compared with people that do not necessarily oppose its introduction and use. Of particular interest, messages related to the rule vaccine had a 96.26% probability to depict negative sentiment, a particularly high probability also when compared with negativity for COVID-19, Freedom and Green Pass in green pass opposition chats (90%, 88% and 85%, respectively), thus providing strength to the hypothesis that vaccine scepticism is the primary reason to oppose the green pass.

Rules and lemma frequency: the interplay between vaccines and green pass

To further understand the relationship between the topics “Green pass”, “Vaccine”, “Freedom” and “COVID-19”, we analysed the most frequency used lemmas when the discussion is about one of such topics (as determined using the associated rules). For the rule “COVID-19”, the lemmas “green”, pass” and “vaccine” were among the most used (**Fig. S1A**). For the rule “Freedom”, as expected, lemmas associated to legal terms were overrepresented, as well as “green” and “pass” (**Fig. S1B**). For the term “Green Pass”, we could not identify “vaccine” among the most relevant and used lemmas, although we identified lemmas associated to legal terms including “freedom”, “law”, “article”, “can” and “must” (**Fig. S1C**). Instead, for the rule “vaccine”, we could identify “green” and “pass” among the most relevant and significant lemmas (**Fig. S1D**). As our previous results indicate, despite our analysis is focused on green pass opposition chats, vaccines constitute a widely discussed topic, which even dominates the discussion about the green pass. In line with our previous observations, here we show that green pass discussion takes place when vaccines are being discussed, but not *vice versa*. This might suggest that green pass critics tend to share anti-vaccine views, but do not wish for their argumentations against the green pass to be revolved around their anti-vaccine views. Rather, they prefer to support their position discussing limitations to personal freedom and advancing legal considerations.

Figure 1

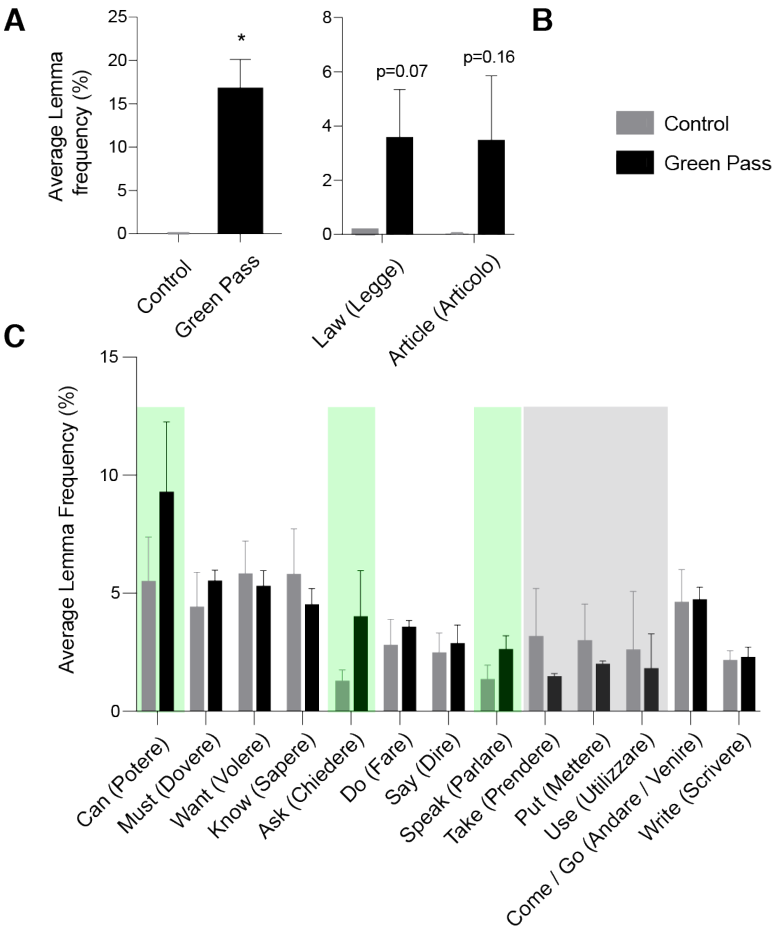

*Figure 1. Average lemma frequency (in percentage) in control vs green pass opposition chats. Average lemma frequency (in percentage) for "Green Pass" in control (grey bar) vs green pass opposition chats (black bar) (A). Average lemma frequency (in percentage) for legal terms in control chats (grey bars) when compared with green pass opposition chats (black bars), extracted from the 20 most used words in the green pass opposition chats (B). Average lemma frequency (in percentage) for action terms in control (grey bars) versus green pass opposition chats (black bars), extracted from the 20 most used words in both control and green pass opposition chats. The green background highlights the most relevant action terms that are overrepresented in the green pass opposition chats, whereas the grey background highlights the most relevant action terms that are overrepresented in control chats (C). *p<0.05, t-test. Error bars represent SEM.*

Table S2

Number	Lemma, symbol or expression	Frequency (%)
1	😂	18.1
2	Know (sapere)	5.9
3	Want (volere)	5.5

4	Can (potere)	4.7
5	🤣	4.3
6	Must (dovere)	4.1
7	Ok	3.4
8	Take (prendere)	3.4
9	Hello (ciao)	3.2
10	See (vedere)	3.1
11	Put (mettere)	3.1
12	Do (fare)	2.6
13	Say (dire)	2.6
14	Ah	2.5
15	🌚	2.5
16	2	2.5
17	Parrot (pappagallo)	2.4
18	❤	2.4
19	Cage (gabbia)	2.4
20	Go (andare)	2.3

Table S2. The 20 most used lemmas, symbols, or expressions in control chats. *The table lists the most frequently used lemmas), symbols or expressions (in percentage) on average across each individual control chat (n=5).*

Table S3

Number	Lemma, symbol or expression	Frequency (%)

1	Can (potere)	9.3
2	Green	9.2
3	Link	8.6
4	Pass	7.5
5	Must (dovere)	5.5
6	Want (volere)	5.3
7	Know (sapere)	4.5
8	Freedom (libertà)	4.1
9	Ask (chiedere)	4.0
10	Vaccine (vaccino)	3.8
11	Message (messaggio)	3.8
12	Do (fare)	3.5
13	Law (legge)	3.5
14	Article (articolo)	3.4
15	Hashtag	3.1
16	Shop owner (esercente)	2.8
17	Say (dire)	2.8
18	Speak (parlare)	2.6
19	Square (piazza)	2.5
20	Come (venire)	2.5

Table S3. The 20 most used lemmas, symbols or expressions in green pass opposition chats. The table lists the most frequently used lemmas), symbols or expressions (in percentage) on average across each individual green opposition chat (n=5).

Figure 2

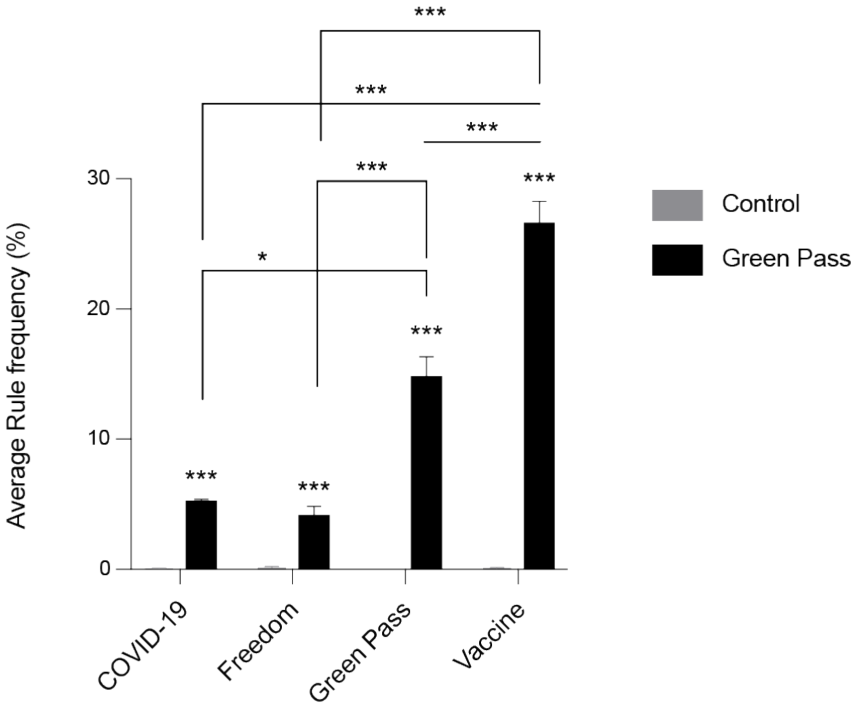

Figure 2. Average rule frequency (in percentage) in control versus green pass opposition chats. *Average rule frequency for terms grouped under the rules "COVID-19", "Freedom", "Green Pass" and "Vaccine" in control (grey bars) vs green pass opposition chats (black bars). *p<0.05; ***p<0.001, t-test. Error bars represent SEM.*

Figure 3

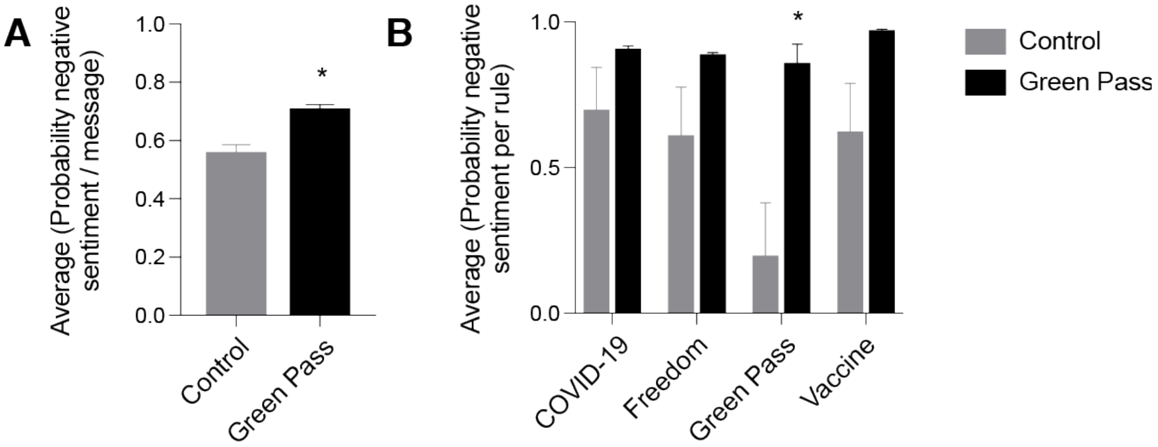

*Figure 3. Sentiment analysis in control versus green pass opposition chats. Average probability of negative sentiment in messages published in control (grey bar) versus green pass opposition (black bar) chats. (A). Average probability of negative sentiment per rule in control (grey bars) versus green pass opposition chats (black bars). The following rules are taken into consideration: "COVID-19", "Freedom", "Green Pass" and "Vaccine" (B). 0 indicates the maximum likelihood for an average message to display positive sentiment, whereas 1 indicates the maximum likelihood for an average message to display negative sentiment. *p<0.05, t-test. Error bars represent SEM.*

Figure S1

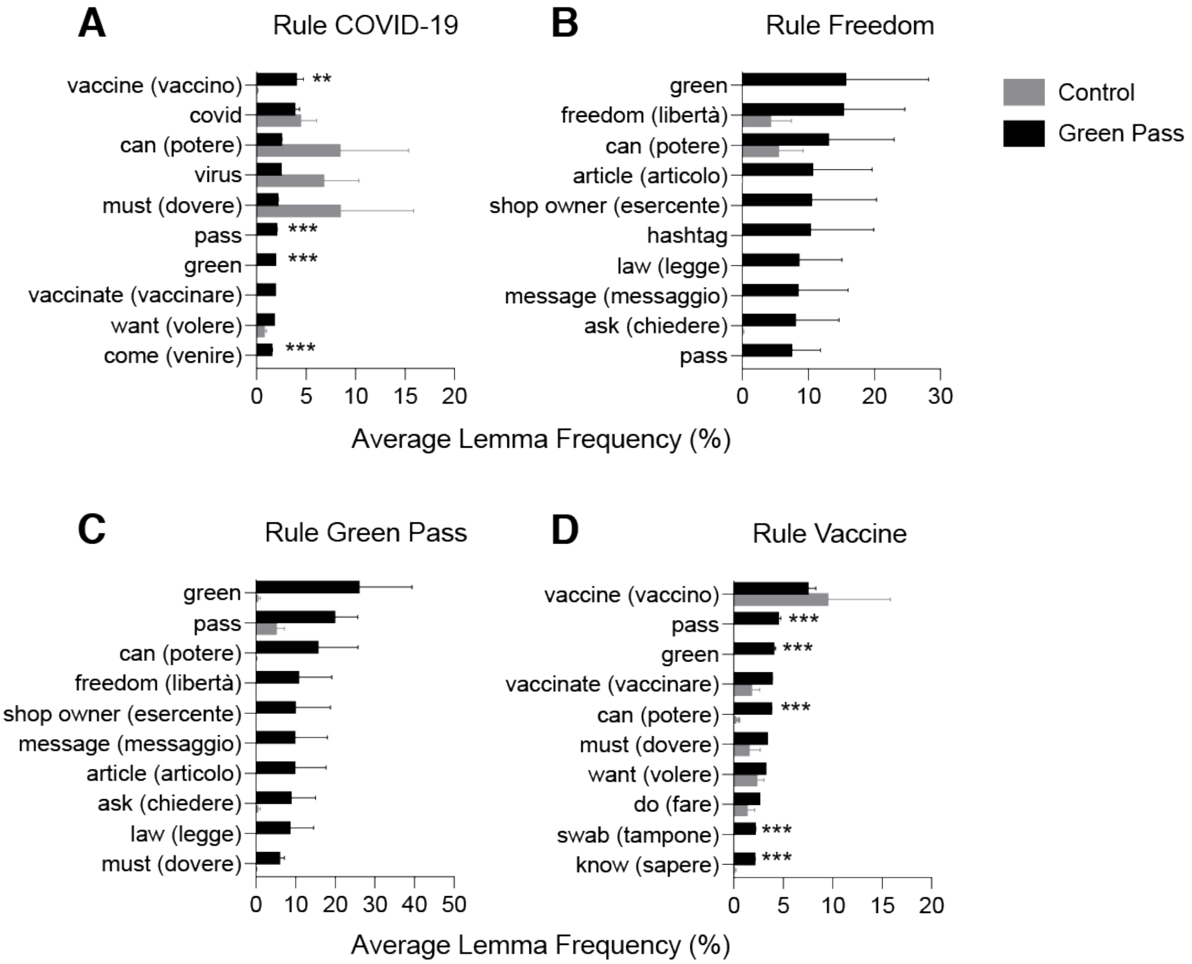

*Figure S1. Average lemma frequency (in percentage) per rule in control versus green pass opposition chats. Average lemma frequency in percentage for the 10 most frequent lemmas in green pass opposition chats (black bars), compared with their relative frequency in control chats (grey bars), extracted from messages scoring a positive value for at least one of the rules: COVID-19 (A), Freedom (B), Green Pass (C) and Vaccine (D). **p<0.01; ***p<0.001, t-test. Bars represent SEM.*

Qualitative results

Green pass and vaccines

The qualitative analysis supports the findings described in our quantitative analysis: Although our analysis is focused on chats discussing the green pass, users often start debating about related topics, including the risk-benefit profile of COVID-19 vaccines, their efficacy and their use. Of note, moderators often ask participants to stay on topic and avoid discussing these parallel issues. There are two main reasons: one is to avoid conflict, as a (small) fraction of individuals who position themselves as anti-green pass are pro-vaccinations; the other is to avoid floods of misinformation which could discredit what the moderators perceive as a much-needed debate:

> *On the other hand, it is a big mistake to take a stance on vaccines. Those who want to do so should do so. The point is only to be against this limitation of freedom and many vaccinated people are against the green pass. Do not introduce divisive or extremist elements that vote the initiative down (university, south, Pos. 742)*

Users themselves are very aware of how hard it is to discuss about the green pass without discussing about the reasons for which it is needed:

> *how can one ignore the vaccine issue if it is literally the main option for getting a pass?? (university, north, Pos. 6693)*

As stated above and as noted in the quantitative analysis, these no-green pass chats have de facto been a proxy to discuss vaccines. Users know the green pass was introduced as a nudging measure to avoid mandatory vaccination. Nevertheless, they do not perceive this strategy in a positive way. Even if there are other ways to receive a valid green pass (i.e recovery from COVID-19 or testing), vaccination is the most obvious and less burdensome one. Users perceive this as a cunning imposition which possibly makes them even angrier than mandated vaccines:

> *I am against the green pass because I see it as a coercive and hypocritical tool put in place by the government because if they saw the vaccine as a safe way, they should have the consistency to make it compulsory and instead they don't bother to do so (university, south, Pos. 1807)*

> *the green pass is a way of circumventing compulsory vaccination. The green pass is an "incentive", said to be very soft, but in fact it is a compulsory requirement. (university, center, Pos. 14716 – 14718)*

Even though, as discussed above, moderators would prefer to disentangle the discussion about green pass from the topic of vaccinations, pointing out that even someone who is vaccinated could hold no-green pass positions, most of the users share common critical beliefs about vaccines:

> *It is becoming increasingly clear from the scientific literature that 1) There are very effective treatments for Covid that indicate that vaccines are not at all essential. 2) Vaccines often have serious short-, medium- and long-term side effects, there is a well-founded fear that they could induce serious pathologies (tumours, autoimmune and degenerative diseases, sterility...) and they are still at the experimental stage. 3) Vaccines facilitate the development of variants, many of which are particularly virulent, and should not be carried out during epidemics, let alone pandemics. 4) Vaccines do not absolutely protect against Covid as they are said to do, i.e. those vaccinated may become infected and may in turn infect others... so they should not have a Green pass unless they too are swabbed... (university, center, Pos. 3572 – 3579*

Users are especially afraid of possible side effects. This narrative proposes that the vaccine is worse than the disease it is meant to prevent:

> *who can guarantee that I will not have serious effects as a result of the vaccine, that could harm my future? Who will compensate me for any damage? (university, north, Pos. 25293 – 25294)*
>
> *Statistics show that the number of deaths due to Covid is the same as the number of deaths due to the vaccine, only that the number of deaths due to Covid is much overestimated (the number also includes deaths due to other causes but catalogued as Covid because they are positive to the test), while deaths due to the vaccine (not to mention cases of serious adverse effects) are much underestimated because only passive surveillance is done, and poorly. (university, center, Pos. 15682 – 15688)*

Moreover, according to several users, there is no evidence that vaccines work: they do not prevent the spread of the disease, and are less effective and more burdensome than alternative therapies to reduce the symptoms and avoid ending up in intensive care (the most quoted are hydroxychloroquine, cortisone, heparin, ivermectin, nonsteroidal anti-inflammatory drug, and hyperimmune plasma transfusions):

> *We must rebel, this vaccine is a gene therapy with no guarantee that it will work. Vaccinated people are just as infectious as unvaccinated people, it is clear that this vaccine does not protect against COVID. (university, north, Pos. 2612)*
>
> *It is written in all official documents of the pharmaceutical companies and the WHO that there is no evidence that vaccination will stop the spread of the virus. (university, north, Pos. 3385)*

Finally, some users suggest that vaccines could be part of a bigger scheme, again orchestrated by governments and covert powers, possibly aiming to reduce the world's population.

> *Overpopulation, they have been saying this for years, and the Vax in my opinion serves to solve that problem, not covid ... (university, south, Pos. 2343)*

> *Their aim is to manipulate human beings by injecting them with a serum containing graphene, which can react with certain frequencies and modify the behaviour of cells. By changing the behaviour of cells, you can change the behaviour of human beings. (generic, Pos. 72471)*

Beyond vaccines: Green pass, legal aspects and personal freedom

Despite vaccines being the predominant topic in these chats, the majority of individuals do not make use of arguments related to vaccines, including conspiracy theories about vaccines, to justify their opposition to the green pass. Rather, they claim the green pass is an illegal measure and it is discriminatory:

> *IT IS CLEAR THAT THE GREEN PASS IS AN INSTRUMENT OF POLITICAL DISCRIMINATION THAT HAS NO RELATION TO THE ACTUAL HEALTH STATUS... (university, center, Pos.* ***3572 – 3579)***

> *The green pass is clearly unconstitutional and discriminatory in nature and is a purely political instrument as it has no scientific basis; the report linked before is very clear about it, then they do not make it mandatory by law otherwise they would be obliged to compensate those who died of the vaccine. (university, center, Pos. 7520 – 7522)*

In some circumstances, users allude to conspiracy theories according to which the green pass is an element of a bigger plan put in place either by governments or by covert powers to achieve other ends, usually the institution of a totalitarian regime:

> *Do you still have to realize that even if the Regime decides to withdraw the COVID PASS, to let you go back to work, you have already become*

> *citizens of a totalitarian Regime? Citizens of a lousy Regime based on lies, on the progressive elimination of freedoms, on the violent suppression of dissent? (generic, Pos. 2127)*

Many users believe the green pass is a serious limitation of personal freedom. This argument is developed following three main threads, in order of importance: normative, consequentialist, and principialist. On the normative side, users appeal mostly to the Italian constitution (art. 13 and 120), to law 196/2003 (personal data protection code), and to the Oviedo convention:

> *the "green pass" cannot be checked because it is discriminatory, prejudicial to privacy and violates the following articles of law: - Art. 187 of the TULPS Regulation: a commercial operator is obliged to welcome in his business any person, without discrimination, under penalty of a fine up to €3000,00.- Privacy Law: no one can force us to provide information about our health conditions.- Art. 120 Italian Constitution: no one can limit the freedom of movement of the individual in the territory of the Italian republic. - Art. 13 Italian Constitution: no one may restrict personal freedom without a provision of the Judicial Authority on facts concerning the individual. (generic, Pos. 3448)*

> *Add that we will respect all the anti covid security measures (social distancing, hygiene, mask). With regard to the reference to laws and treaties, don't we want to mention the convention on human rights, the Oviedo treaty and the Supreme Court ruling stating that the health of the individual cannot be sacrificed for the sake of collective health? don't we want to mention the principle of self-determination? (university, center, Pos. 395 – 397)*

On the consequentialist side, users fear that the green pass will lead to a system of capillary social control, repression of dissent and loss of critical thinking capabilities.

> *Look at the Chinese social score system to understand the crazy direction of these actions, typical of dictatorial systems and not of advanced democracies. (university, south, Pos. 3755)*

> *By now I think these people are lobotomized and probably don't even know the word FREEDOM (university, south, Pos. 1255)*

A minority of users tries to build a principlist argument, balancing the concepts of freedom and life. Their conclusion is that life and freedom are equally important principles, hence it's unjust to protect life limiting freedom.

> *If the answer to the question is that life is more important than liberty, then all the liberticidal laws made so far are justifiable and I would say almost fair, I can also understand why the green pass, a blatantly discriminatory law, is considered fair by many.*
>
> *If the answer to the question is freedom, it is clear that everything that has been done so far is considered a mistake regardless of whether a particular law was made to save lives.*
>
> *We come to the last answer, the most balanced one for me at least, that life and freedom are of equal importance. In view of this answer, it is clear that taking precautions to limit contagion and death is right and proper, so limitations will be inevitable (such as social distancing, masks indoors, limiting seating etc.), but at the same time it is important to preserve the freedoms of all citizens. (university, center, Pos. 14996 – 15012)*

The three arguments converge on a single conclusion: the green pass and the system of control it creates are either seen as tools in the hands of dictators or as preparatory tools to gather power.

> *What kind of disgusting nightmare do we want to bequeath to our children? A Health Regime? A Regime that brutalises the minds and bodies of its citizens on a daily basis? Enough! Rebel! (generic, Pos. 2127)*
>
> *We are living in a health dictatorship and political authoritarianism that must be opposed. I wonder if a general acting as a commissioner who comes out with absurd words about wanting to flush out the 'unvaccinated' house by house? These people must leave the government. We must demand to go to the polls again. (university, center, Pos. 5904 – 5906)*

Action plan

Leveraging on this understanding of freedom, users perceive a clear duty to react. The first and foremost action is understanding who the real enemy is, i.e. not the virus, nor the people who get vaccinated or 'obey to the regime'. The real enemies are the political system and the political representatives who allowed this to happen:

> *It is a political issue everywhere. If we understand this we know who we have to fight, and for sure it's not a virus. (university, north, Pos. 20112)*

In the university groups, users discuss a lot about communication strategies that would allow them to be credible, also because they are aware that their groups might be studied. The most important points regard avoiding 'defusing topics' (i.e. conspiracy theories) and focusing on self-determination. Again, coherently with our quantitative findings, the main issue appears to be the vaccine, for which the green pass is just a proxy.

> *we have been able to ascertain the intense doxing activity also of telegram groups. In short, now that membership is growing, we need a minimum of 'art of war' (or rather strategy, just to avoid accusations of terrorism) (university, north, Pos. 20233)*

> *no disquisitions that go beyond the topic to be defended, such as the existence or non-existence of the virus, the no-pro vax diatribe, the Davis forum, depopulation, mass experimentation, variants, damage, etc. These are all topics on which one has burnt the candle at the stake. These are all topics on which the authoritativeness of many prominent figures has been burned, since they easily fall under the so to speak 'defusing' labels (conspiracist, degree obtained on Google, no Mask, no vax, no test, denialist). (university, north, Pos. 3607)*

Lastly, many users consider protests as valid strategic options to make their voices heard. The options they consider range from flash mobs to general strikes, to occupations of the parliament.

> *Shall we make a flash mob where all the unvaccinated all go in at the same time where they can't? Maybe running so that we are sweaty (so they are afraid to touch us) maybe with a hat that says "the Jew rebels" (generic, Pos. 1007)*

> *You will sign in front of the incredulous eyes of your employer your declaration of non-violent struggle. Your declaration of an all-out general strike. Full stop. Nothing else is needed. There will be 100,000 of us, and we will block Italy, offices, services, production. We will pull the plug of this infamous regime. (generic, Pos. 2127)*

Summary: explaining green pass opposition without involving vaccines

Among those opposing the introduction of the green pass, especially among university students, only few are in favor of vaccinations, and those in favor of freedom of choice are typically hesitant about vaccines. Being aware anti-vaccine discourse has been typically dismissed by a large fraction of Italian society and by the political class as conspiratorial in nature and not worth considering, anti-green pass, often anti-vaccine supporters have oriented themselves towards different argumentations to defend their positions, revolving around legal aspects related to the concept of personal freedom. Our considerations are well summarized by this message:

> *The main argument must continue to be that one must be able to refuse an injection, whatever it may be. The body is mine and I decide. And if you were to be convinced that the serum prevents x% of the infection (as some try to suggest), would our whole battle fall apart? I certainly hope it's not the case. (university, north, Pos. 24367)*

The battle is fought on different grounds than vaccines, but vaccines are what this battle is for.

Other aspects: COVID-19

In the no-green-pass corpus are two main positions about COVID-19 emerge. According to the first, COVID-19 exists but is much less dangerous than what it's communicated by "mainstream media":

> *In addition, in response to the pathetic provocation, I would like to point out that 99% of COVID deaths are of over-80s with multiple pathologies. (university, center, Pos. 2199 – 2202)*

> *COVID exists but you can't stop the world because of it. It's a fucking flu, especially for young people. Many more people have died of the flu and it has never been talked about. (university, north, Pos. 2864)*

According to the second dominant position, COVID-19 does not exist and is yet another element of a bigger plan conceived to limit personal freedoms and eradicate free thinking through fear:

> *Do you realise that you're talking about a virus that nobody anywhere in the world can prove exists? (university, north, Pos. 1328)*

> *The virus has never been isolated or purified. (university, north, Pos. 6509)*

At the junction of these two narratives, COVID-19 would be a strategy to pursue other means:

> *THE VIRUS IS JUST A MEANS TO ACHIEVE OTHER GOALS THAT HAVE NOTHING TO DO WITH HEALTH PROTECTION (university, center, Pos. 8092 – 8095)*

Other aspects: Expertise

If COVID-19 does not exist or is not particularly dangerous, then the need for measures such as the green pass would be unfounded. These beliefs are supported by a wide network of "experts", that according to users are brave free thinkers who are not afraid of speaking their mind and standing against these covert powers:

> *In addition, the most important doctor we have in Italy, Dr Remuzzi with H index 189, has long since drawn up an approved treatment protocol. Go to the website of the [name] Negri Institute and find out more. Dr. Scoglio, candidate for the 2018 Nobel Prize, should also be considered. (university, center, Pos. 14640 – 14643)*
>
> *covid can be treated at home, with medication. There is a group of volunteer doctors who do just that. "Terapie domiciliari COVID", a very popular facebook group. (university, south, Pos. 1974)*

> *Listen also to Dr Citro, Dr [name] Montanari, Dr Bolgan, to what they say. [Authorities] forced people to get vaccinated with fear, and blackmailed young people with the green pass. There are many adverse reactions and they don't tell you that, so resist for your own good. (university, center, Pos. 4198 – 4200)*

> *The mask does not protect against viruses. Instead, it creates colonies of bacteria that you breathe in, as well as other filth that I won't tell you about, not to look like a conspiracy theorist. My colleague's comments on Dr Gatti are right. A great nanopathologist. (university, north, Pos. 742)*

> *According to Dr Delgado, it is not a virus that causes the disease. I will explain this when we meet. (university, north, Pos. 3485)*

Other aspects: Preferred measures

Among those who believe that COVID-19 is actually an issue to be contained, some try to delineate alternatives to the green pass. These include the use of masks, social distancing, tests, and dual teaching (both in presence and online).

> *Exactly, you must respect all the rules to prevent contagion and therefore masks and distancing. (university, south, Pos. 1467)*

> *if we really want to be sure that the virus does not spread in the university, shouldn't the swab be used for everyone who enters the university, as it is the only instrument with a high percentage of detection of the virus? (university, north, Pos. 25297)*

> *However, I would like to see mixed teaching, both face-to-face and online, at least in the first semester so as not to increase the risk of infection and to allow everyone to get vaccinated. The situation in [place], with transport and everything, means that the risk of contagion is too high, even for those who are vaccinated and may be carriers. I don't feel like taking the responsibility of walking around in [place], even if I'm vaccinated, and putting other people's life at risk. (university, center, Pos. 2095 – 2102)*

However, in the same groups there is a strong critique of the dehumanization caused by online teaching, and tests are perceived as burdensome (economically and physically) and as unfair:

> *In spite of the effort to reach the university, it is not real university what you do online. [The real one is] made of people, looks, REAL dialogues; it is precisely the effort and the time spent to go to the university that sanctions its founding and formative value. Distance learning is not an appropriate cultural medium. (university, north, Pos. 19204)*

> *the test becomes an economically limiting tool for the individual, since university students are not guaranteed free access to this service at all, which puts an economic burden on those who choose not to vaccinate. (university, north, Pos. 25298)*

Other aspects: Anti-test and anti-mask positions

Although more testing and a systematic use of masks are sometimes suggested as a preferred protection strategy, many users have concerns about both. Some users think that tests and masks do not work, some think tests are dangerous as while collecting a mucus sample it is possible to damage the brain, some believe that masks are dangerous as they create bacterial colonies.

> *I still don't understand... (it's rhetorical and sarcastic) why for the most contagious virus that spreads with a single droplet - with aerosol even, in the air... you have to pierce all the way to the encephalic barrier and up to the pineal gland? Maybe because otherwise you don't assimilate graphene oxide & who knows what else? Vets have long used nasal vaccination. Ps. There have been cases of rhinoliquorrhoea, i.e. loss of cerebrospinal fluid, dizziness, abnormal migraines, etc., but of course, as with everything else, everything is covered up and minimised. (university, north, Pos. 11697-11698)*

> *The mask does not protect against viruses. Instead, it creates colonies of bacteria that you breathe in, as well as other filth that I won't tell you about, not to look like a conspiracy theorist. My colleague's comments on Dr Gatti are right. A great nanopathologist. (university, north, Pos. 742)*

Other aspects: Reliance on anecdotal evidence

Users often bring information to support their claims. Sometimes they link to blog posts, seldom to scientific studies or to statistical analyses. Sometimes they engage with such information critically, sometimes they don’t. Of note, stories based on anecdotes and personal narratives tend not to be questioned:

> *My grandfather died with covid. We followed what the doctors said about treatment at home for my grandmother. She survived. My grandfather wanted to follow the standard procedure instead. 2 weeks worsening. Intensive care and death. (university, center, Pos. 13863 – 13866)*

> *I spoke to a doctor from [place]. Do you know what they do to make it look like only the unvaccinated are in the ICU? When covid patients come in, even those vaccinated with two doses, they have orders to move the vaccinated to other wards and leave the unvaccinated in the ICU. (university, north, Pos. 24524)*

Discussion

Our analysis clearly shows how the green pass has become a proxy and a catalyser for vaccine scepticism. Especially during this time, people and politicians supportive of vaccines strongly oppose vaccine scepticism or denialism, and the discussion about the dangers of vaccines, as well as the conspiracy theories and the misinformation in general, are not considered relevant and are "silenced", since these positions are not backed up by scientific evidence. Anti-vaccine supporters have come to learn that shifting their focus on the green pass, allows them to bring new arguments which are more likely to be heard – to indirectly counter the use of vaccines. In fact, questioning the validity of the green pass, rather than that of vaccines, is seen as less socially problematic albeit it remains strictly connected to the discussion about vaccines. In practice, the green pass has become the fig-leaf of the anti-vaccine movement.

That said, it is also important to note that tensions and diverging narratives exist, even within the groups under analysis. As our results show, moderate positions (i.e. COVID-19 is an issue, but the green pass is not an appropriate measure) coexist with conspiracy theories (i.e. COVID-19 does not exist and COVID-19, vaccines and the green pass are part of a bigger plan). De facto, opposition to the green pass is what glues together these opinions and attitudes. This opposition is often justified on the grounds of a naïve idea of freedom, conceptualized in a normative, consequentialist, or principialist form.

Based on our findings, we believe it is possible to trace some recommendations for public health authorities and political institutions engaging with communication on these topics:

1. Acknowledge the doubts of anti-green pass individuals without dismissing their opinions and arguments as ramblings;
2. Disambiguate the purpose of the green pass: it should be made clear it is a tool intended to incentivize vaccinations – and thus to protect people; not only people who cannot get vaccinated, but also to protect everybody's personal freedom (i.e. those who are not willing to risk to contract the virus but still desire to enjoy a meal in a restaurant, watch a theatre play or a football match in a stadium, etc). We see this discussion as a reminiscent of the long-standing debate about smoking in closed environments.
3. Since freedom is an important topic, counteract the models of freedom in which the opposition to the green pass is grounded, offering alternatives, e.g. Rawls'

"greatest equal liberty" principle (Rawls 2005a, 325–30), according to which each person should be given the most extensive basic freedoms that are compatible with another person's freedom.

4. Clarify the legal basis of the green pass, explaining how it is founded and regulated in existing jurisprudence, and how its scope and application is defined and limited by the contingency of the pandemic. It is necessary to explain why it has a specific "expiry date" and under which circumstances and for how long people should expect these measures to be in place;
5. Keep informing about vaccines, with a specific focus on transparency and risk-benefit balance. In this context, complement as much as possible narratives based on data and scientific evidence with personal narratives (still backed up by science), as according to literature (Drewniak et al. 2020) and to what we found in our data, they are easier to relate to and can be more effective.

Ethical considerations and recommendations

A plea for active social listening

Communication is a key component of human life. The ability to communicate privately with others can be understood as an expression of the right to privacy. Privacy, in turn, is not a luxury that can be easily overridden by other, seemingly more urgent or more important needs. Rather, it is a fundamental human right recognized by the UN Declaration of Human Rights and many other international and national treaties. The current pandemic has presented us with tricky dilemmas regarding the protection of both privacy and public health. Although there is no doubt about the need for effective management of the pandemic, concerns have been voiced that "measures taken to control the spread of COVID-19 have negatively impacted the enjoyment of the right to privacy and other human rights" (Cannataci 2021). These concerns become even more acute when measures are coupled with AI technology that can enhance not only analysis and forecasting but also the ability to effectively target the behavior of groups and individuals (Office of the United Nations High Commissioner for Human Rights 2021). The key ethical question is therefore how effective communication and management during important public health crises such as pandemics is possible without undermining privacy as a human right.

Telegram grants end-to-end encryption, and encrypted communication might grant a sense of safety to users. In fact, due to this perceived safety, often it's chosen for illegal activities – as it happened for the sale of false green passes (AGI 2021). But when a curious user acquires access to the group, either directly or with social engineering techniques, he has access to the entire history of the chat, no matter the encryption.

It is worth noting that similar or related groups often cross-share messages; when a message is shared, it incorporates a link to the original chat where it was posted. Thus, scraping chats for 't.me' links it is rather simple to obtain access to related groups. Finally, it is important to mention that often these groups use bots offering more advanced moderation features, e.g. silencing a user for a specified amount of time. As bots come to users as black boxes, it would not be difficult to load them with malicious features, e.g. sending the links of the chats where they are used if specific rules fire.

Even when users do not use their name and surname as their username, still there are many possible strategies for reidentification. Users might share emails, locations, even pictures. Crossing this information and identifying a person is just a matter of amount of data, time, and commitment.

Having proven that the approach and the techniques detailed in this paper can provide useful and deep insight on critical topics debated telegram groups, we still tend to think that these techniques should not be applied broadly for social listening. We live in a time in which societies are already suffering a progressive loss of trust, and techniques of 'passive' social listening – intended as collecting information from digital communities without engaging with them – can only worsen the situation. Passive social listening, as detailed in this paper, is incredibly powerful, as it can extensively and rapidly map communities, measure their discussions, potentially help predicting protests and violent actions. On the other hand, 'active' social listening – intended as actively asking people their opinion on delicate topics such as vaccine distribution strategies or safety measures – is slower and less comprehensive, as it depends on creating efficient bidirectional interfaces between the public and authorities. But it has a big advantage: it can build trust rather than undermining it further. Engaging directly with communities, offering concerned people the possibility to voice their worries can create a sense of not only being listened to, but of also being heard, recognised, and valued.

A recent example for an active social listening tool is PubliCo (Spitale, Merten, et al. 2020), an online platform that collects data on public perception of the pandemic and its management. Following a participatory, citizen science approach, it invites users not only to provide data, but also to suggest new survey items or to research the database with queries of their particular interest (Spitale et al. 2021a).

Transparency and recommendations

The software and the procedure we developed are subject to the dual-use problem. In non-democratic regimes they could be used not only to map and understand dissent, but to eradicate it. Our decision to share it is motivated by three reasons: first, science should be open and transparent in its objectives, means, and methods, not only in its findings. Second, as Steven Levy noted: 'If you don't have access to the information you need to improve things, how can you fix them?' (Levy 2010, chap. 2). Pavel Durov, Telegram's founder, stated that 'Telegram must continue to serve the world as an example of a tech company that strives for perfection and integrity' (Durov 2020). If Telegram wants to stay true to that claim, the company needs to know how a characteristic of their software can be exploited as a vulnerability compromising users' privacy. Third: if a non-democratic regime would want to develop a similar system, it could do it anyways – unless this vulnerability is fixed.

Limitations

As we collected our data from public telegram groups, our sampling is not representative of the general anti-green pass population. We do not have any information about the magnitude of the phenomenon, nor do we have demographic variables to stratify the analysis. However, the sample is relevant for the scope of this study and we can characterize why and how these groups oppose the green pass, drawing reliable conclusions and outlining possible approach strategies. Our approach to thematic analysis departs from standards: in thematic analysis data should be disassembled and reassembled in a different shape to reveal its themes and patterns (Braun et al. 2018; Braun and Clarke 2006) with a bottom-up approach to coding. Codes should emerge during the analysis to capture emerging and unforeseen phenomena – which contrasts with the very notion of autocoding we employed. To mitigate this, we adopted an iterative process with continuous testing, analysis, and expansion of the rules. Still, we believe autocoding is a good compromise to map the content of large volumes of data in a reasonable time.

Conclusion

Through our social listening analysis on Telegram chats we conclude that a large fraction of anti-green pass individuals share anti-vaccine views. We also show they generally do not argument their opposition to the green pass with anti-vaccine rhetoric, but rather focus on legal aspects and limitations of personal freedom. We suggest public health and political institutions to provide a legal explanation and a context for the use of the green pass, as well as to continue focusing on vaccine communication to inform hesitant individuals. Finally, we point to the ethical ramifications of our research and propose ways to ensure social listening analysis is transparent and ethically sound. Further work is needed to define a consensual ethical framework for social listening for public health.

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7. The value of people's voices

Mixed methods approaches offer significant advantages when studying real-life human phenomena. As I keep saying, it is all about magnitude and meaning. We are interested in the prevalence of a given phenomenon, and with the strength of its (correlational or causal) association with other phenomena or with specific properties. But at the same time, when we are talking about humans, we want to understand what something means – to those going through it, and to the society. We acquired quite some experience with qualitative analysis of patient narratives over the last years, resulting from the creation of DIPEx.ch, a research group based at the IBME and connected with the DIPEx international community, dedicated to the systematic collection and analysis of stories of health and illness, told by the protagonists. Even without specific funding, it would have been blind not to apply this kind of approach to the experiences of COVID-19 survivors – and that is precisely what we did, together with colleagues from other 13 countries belonging to the DIPEx international group. While the analysis of the resulting material is still ongoing, the experience highlighted some novel methodological and infrastructural possibilities. Data sharing is in general a good practice in research projects – and a duty to taxpayers; in the context of a pandemic, it becomes even more important. Comparing experiences of patients coming from different countries and treated in different healthcare systems can help understanding what works and what does not, in order to deliver better care (i.e: more fair and more effective). But data sharing to be of any use requires comparable data, collected with the same methodology, analysed with the same approach, archived with the same properties and metadata. In Chapter 7 we detail what we consider the state of the art in working with patient narratives, grounding the approach in literature, explaining the methods, and highlighting future possibilities to push even further the reusability of these data.

Patient narratives – a still undervalued resource for healthcare improvement

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Abstract

In recent years, patient narratives have gained increasing attention as a valuable source of insights into the subjective experience of healthcare. This paper outlines a best-practice approach to the collection, analysis, and use of patient narratives, based on current literature and on the experience of developing the Swiss Database of Individual Patient Experiences (DIPEx). The DIPEx project aims to provide a systematic and methodologically rigorous collection of patient narratives on various health situations and topics. This paper presents and details the DIPEx approach as a current standard in the field, offering a comprehensive overview and discussing the potential uses and benefits of patient narratives: improve healthcare practice, empower patients and caregivers, help structure better communication in healthcare, and contribute to medical teaching and learning.

Keywords

Qualitative research, patient experiences, interviews, narration, patient-centred care

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Introduction

Research on patient narratives has steadily gained momentum over the last decades. For good reasons: patient narratives are unique windows on the subjective aspects of the healthcare experience – which is a very relevant aspect of healthcare. Work on patient narratives can build empirical foundations for better patient-centred care; inform the development of Patient Reported Experience Measures (PREMs) and of Patient Reported Outcome Measures (PROMs); empower patients and caregivers; help structure better communication in healthcare; contribute to medical teaching and learning. In a nutshell, narratives help us understand the very meaning of health, illness, and care for the key stakeholders of healthcare: patients (Pallai and Tran 2019). Patient narratives can bring pack people's voices in patient centred care; they are evidence, as in 'evidence-based medicine', complementary – not alternative – to quantitative evidence. Nevertheless, they need to be collected and studied with method and rigour to contribute to designing better healthcare.

Individual patient accounts that appear more or less randomly in the medical literature and media may be appealing and insightful, but come with obvious limitations. They cannot capture variations, nor do they routinely provide detailed information about disease, diagnosis and treatment. A systematic collection, however, provides a clear methodology and transparent analysis that is amenable to critical scrutiny. Results are contextualized and discussed, including other qualitative studies as well as quantitative work, to increase validity and reduce potential bias.

In this article, based on current literature and on our hands-on experience of developing a Swiss Database of Individual Patient Experiences (DIPEx), we detail a standardized, best-practice approach to the collection, analysis, and use of patient narratives, in the form of semi-structured interviews – keeping in view that standards are currently evolving

(Deutsches Netzwerk Gesundheitskompetenz 2022). The Swiss DIPEx project aims to provide a systematic and methodologically rigorous collection of patient narratives on various health situations, as diseases like dementia, chronic pain, Parkinson's, COVID-19, Multiple Sclerosis, rare diseases and others, but also on health-related topics, e.g. Intensive Care Management and Coercion, Pregnancy and prenatal testing, or possible future topics as adolescent obesity, risk of falls in older age, addictive behaviour among adolescents, or vocational reintegration at workplace.

Background

The value of qualitative research has been long recognized in public health and health services research. The focus on methods that encourage participation and provide an deep insight into the subjective experience, which is one of the strength of qualitative research, is now increasingly published and accepted in the mainstream medical literature: Lancet commissions incorporate patient voices (Han et al. 2016), and JAMA has a specific section on narratives (JAMA 2022). The Equator Network, an international initiative seeking "to improve the reliability and value of published health research literature by promoting transparent and accurate reporting", lists qualitative research as one of the main study types in health research (Equator Network 2022; O'Brien et al. 2014; Tong, Sainsbury, and Craig 2007).

Patient narratives can help close the gap between what really matters to the individual patient and what healthcare professionals perceive (Kleinman 1989). Beyond patient centeredness, other dimensions of healthcare quality can be improved. Targeted care, based on patients' needs and priorities, can be more effective and efficient, avoiding unnecessary expenses that do not add value for patients (Porter 2010). The saved resources can in turn be invested to deliver more timely and equitable care. Better understanding of patients' perspectives contributes also to patient safety, e.g., through adapting information procedures to patients' emotional state and current cognitive receptivity. By sharing their experiences and by learning from others with similar conditions, patients and their relatives can feel supported and more able to cope with their disease (Ziebland, Lavie-Ajayi, and Lucius-Hoene 2015).

Patient narratives can also contribute to medical education and teaching, fostering understanding and improving communication. In fact, the creation of a database for a learning system has been identified as one of the core challenges that Swiss healthcare faces today (Biller-Andorno and Zeltner 2015).

Distant reading

To understand how patient narratives have been incorporated in healthcare scholarly work we adopted a ‘distant reading’ strategy (Franzini et al. 2015; Moretti 2013, 49). We used TopicTracker (Spitale and Biller-Andorno 2021b), a Python pipeline to retrieve PubMed entries and to perform Natural Language Processing analyses on the corpus. Our query is fairly simple – but rather specific:

"1975/01/01"[Date - Publication] : "2021/12/31"[Date - Publication] AND ("patient s"[All Fields] OR "patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields] OR "patients s"[All Fields]) AND ("narration"[MeSH Terms] OR "narration"[All Fields] OR "narrative"[All Fields] OR "narratives"[All Fields] OR "narrative s"[All Fields] OR "narratively"[All Fields])

The query captures everything indexed in PubMed from 1975 (i.e. when the combination ‘patient narratives’ appeared for the first time in a paper’s keywords) to 2021.

Our analysis is focused 1. on normalized keywords and MeSH terms to describe the evolution of the field and the main topics; and 2. on normalized journals (i.e: the normalized count of journals publishing this literature), to describe the impact, the target, and the typical audience of these publications. Normalization is performed in the same way for each entity, i.e: normalized entity = count of entity / number of papers. The original dataset is available for replication and further exploration (Spitale 2022).

Our query captures a total of 26739 papers (after duplicate removal).

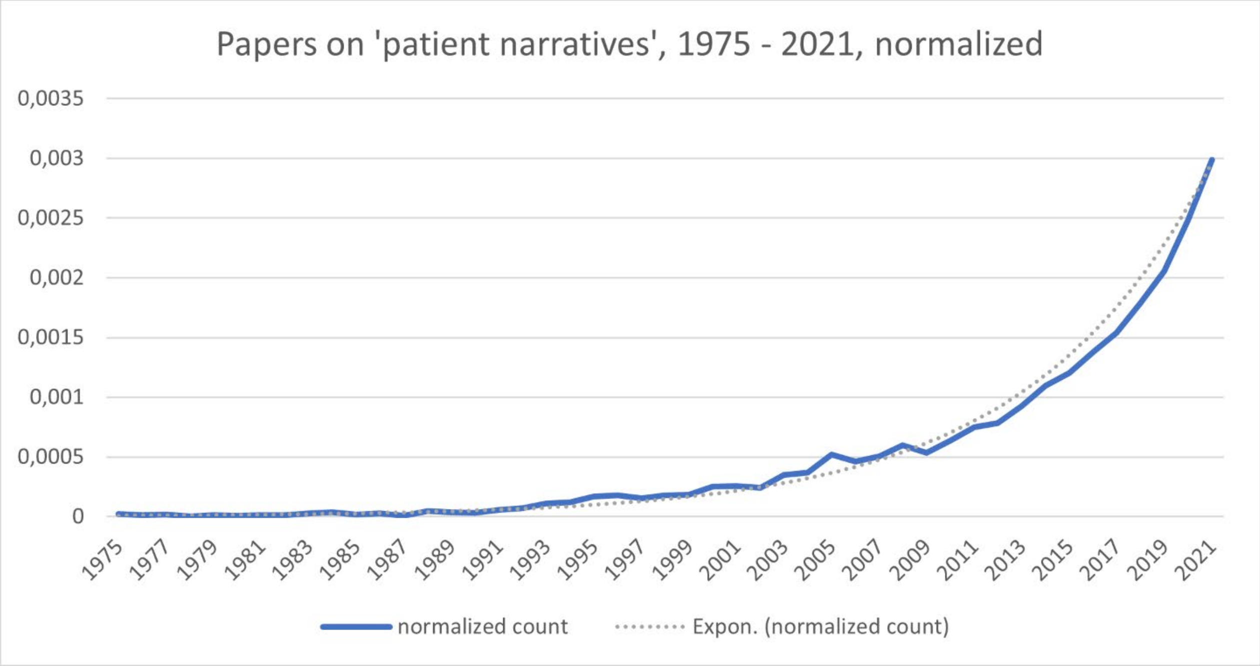

Figure 1, number of articles captured by our query on 'patient narratives', 1975 - 2021, normalized to total articles indexed in PubMed in the same year

It is clear that the last decade saw the start of an exponential growth in publications dealing with ‘patient narratives’. Of note, in 2021 0.3% of all the literature indexed in PubMed touches this topic.

Keywords

The analysis of the most frequent 50 normalized keywords offers a first overview of what this field is about in terms of methodologies, conditions targeted, and context of application of the findings. Keywords focus on:

1. The methodology and the approach, including: analytical approach, empirical approach, philosophical approach, religious approach, qualitative research, natural language processing, patient experiences.

2. The target conditions, including: death and euthanasia, mental health, cancer, genetics and reproduction, depression, dementia, stroke, pain / chronic pain, schizophrenia, diabetes, obesity, breast cancer. The target conditions remain rather stable over time.

3. The context in which this research can have a substantial impact, including: professional patient relationship, palliative care, quality of life, nursing, rehabilitation,

communication, narrative medicine, patient safety, primary care, diagnosis, surgery, prevention, medical education, and quality improvement. Some changes occurred over time in the 'context' keywords, with some relevant new entries, becoming more popular in the last decade, namely: education, patient education, adherence. This suggests a gradual but steady switch of focus towards what we could call 'patient oriented research'.

MeSH terms

The analysis of the 50 most frequent normalized MeSH terms provides confirmation and further insight into what highlighted by the keyword analysis. MeSH terms focus on:

1. the methodology and the approach, including: narration, surveys and questionnaires, qualitative research, nursing methodology research, interviews, psychometrics, evaluation studies, retrospective studies, neuropsychological tests, and randomized control trials.

2. The context in which this research can have a substantial impact, including: interpersonal relations, attitude to health, self-concept, decision making, communication, medical history taking, attitude of health personnel, treatment outcome, social isolation, personal autonomy, verbal behaviour, social support, quality of life, and grief. Of note, starting from 2011 'treatment outcome' becomes the most frequent 'contextual' MeSH term in the corpus, followed by 'quality of life' and 'communication', providing a very clear indication on how patient narratives are mostly used now – informing the development of PROMs.

Journals

Journal trends suggests that although scholarly work on patient narratives tends to be published by discipline-specific journals (e.g: 'Brain and language', 'Social science and medicine'), it is gaining momentum and attention from top-notch medical journals, traditionally less inclined to publish this type of research. Although it is possible to speculate that the COVID-19 pandemic had a negative impact on the field, the most influential, high impact medical publications are accepting more research on patient narratives than before.

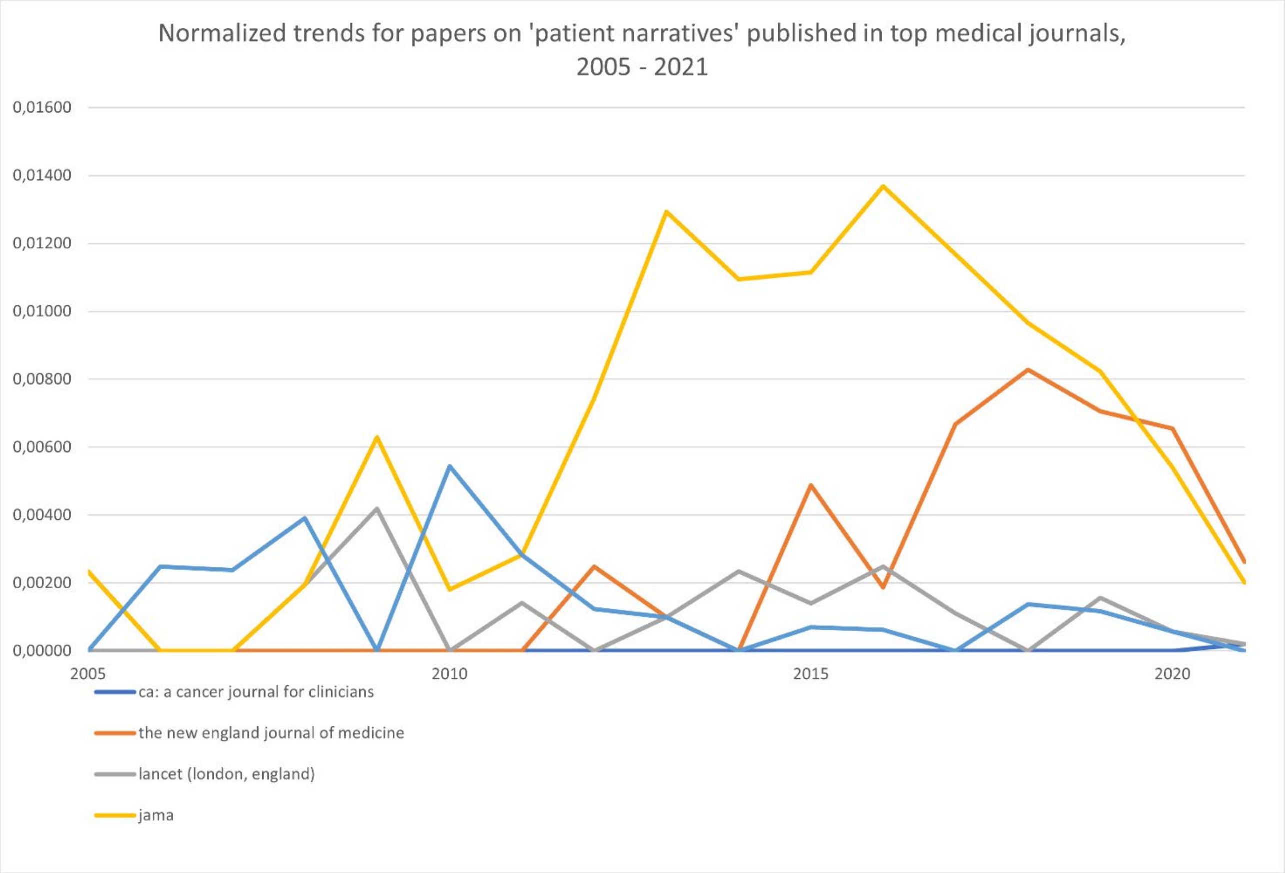

Figure 2, Normalized trends for papers on 'patient narratives' published in top medical journals, 2005 – 2021. Top medical journals have been identified and ordered by their reported impact factor in 2020: CA: A Cancer Journal for Clinicians - 120,83; the New England Journal of Medicine - 74,699; Lancet - 60,392; Journal of the American Medical Association - 51,273; Journal of Clinical Oncology - 32,956

DIPEx International

Distant reading shows how participated and polyphonic the work on patient narratives has become, while maintaining some internal consistency. This richness is benefitting the field, nevertheless we believe that some form of standardization is needed. Standards ensure consistency, comparability, inter-compatibility, and quality of the data, needs that have emerged even more strongly during the COVID-19 crisis: comparing narrative data from different countries allows to compare the influence of structural factors like the healthcare system or response strategies on individual experiences, hence, to identify good practices, and improve quality of care.

Some work in the sense of defining solid standards for research on patient narratives, more specifically on patient interviews already exists, resulting from the joint efforts of the DIPEx International research community. DIPEx is a multi-media approach to collecting, analysing, and disseminating patient interviews, emerged in the early 2000s from the personal healthcare experience of Ann McPherson, a general practitioner, and Andrew Herxheimer, a clinical pharmacologist. The original idea of 'a systematic collection and analysis of interviews with people about their experience of illness with evidence of the effects of treatments, and information about support groups and other resource materials' (Herxheimer et al. 2000) grew over the years, as well as the research community.

DIPEx aims to 'identify the questions that matter to people when they are ill' (Herxheimer et al. 2000). It collects interviews with patients with different diseases that are made available on a website as audio, video, or text, in accordance with the preferences of the interviewee. The idea is to inform patients, to educate healthcare professionals, and to provide a 'patient centred perspective to researchers and those who manage health services' (Herxheimer et al. 2000).

The methodology has been further codified (Ziebland and McPherson 2006; Medical Sociology and Health Experiences Research Group (MS & HERG) 2020), as well as the use and impact of the data for researchers, healthcare professionals, patients, and caregivers (Ziebland and Herxheimer 2008; Ziebland, Lavie-Ajayi, and Lucius-Hoene 2015; Drewniak et al. 2020; Christensen, Parker, and Cottrell 2021).

In the last two decades, DIPEx international has grown into a solid network with research groups in 14 countries – including Switzerland (Ziebland, Grob, and Schlesinger 2021).

The DIPEx.ch approach

In this section we present the current state of the art, the best practices, and the main limitations of this kind of approach in developing our database of patient narratives, an open structure that allows the addition of further modules, providing data that can be used for future secondary analyses in other national or international research contexts, as done for COVID-19. This way, the project and database aim to contribute not only to a smarter but to a wiser health care that is well anchored in patients' needs, values and priorities.

Project definition

A DIPEx project starts defining a 'module'. Each module targets a specific health condition. The choice of the target depends on several factors, including evidence of knowledge gaps, suggestions by healthcare institutions, or requests from patient organizations.

Modules are conducted by a team of expert researchers, with experience in qualitative research, who received specific formal training (Medical Sociology and Health Experiences Research Group (MS & HERG) 2020), and with a good command of multiple languages (a factor of crucial importance in a multilingual country such as Switzerland).

DIPEx Switzerland obtained a clarification of responsibility on the methodology from Zurich's Cantonal Ethics Committee, stating that 'it does not fall within the scope of the Human Research Act' (BASEC-Nr. 2017-00678). This was later extended to the entire country, allowing to 'carry out the project throughout Switzerland without ethics committee approval' (BASEC-Nr. 2018-00050). In case new modules include substantial methodological changes, they are subject to a second round of ethical approval.

After a review of the available literature, the research team defines a research question and a topic-informed interview guide. It comprises an open narrative section and follow-up questions that allow understanding specific topics, stemming from the research question. Each interview guide receives feedback from a module-specific advisory board, composed of healthcare professionals, other researchers, and patients. The feedback addresses both structural factors (e.g: appropriateness of the questions, salience) and linguistical factors (e.g: use of language-specific, non-translatable words, sentences or constructs). Our team of researchers comprises English, German, French and Italian speakers, with English being the common language. The interview guides are typically drafted in English, pilot-tested, and subsequently translated. The translation is focused on maintaining an accurate interpretation of the questions, as opposed to an accurate linguistic reproduction (Schaffner 1997).

An example of interview guide is provided as appendix 3.

Data collection

As typically qualitative research aims for transferability and not representativity (Morse 2000; Marshall 1996), the sampling strategy follows a maximum variation approach (Coyne 1997). The idea is to understand which variables could influence the experience (age, gender, living arrangement, family background, condition-specific factors, …) and to represent these possible variations in the sample (Herxheimer et al. 2000). Participants are recruited through patients' organizations, healthcare institutions, registries, although the strategy may vary depending on the target condition. The interviews are performed in the language participants are most comfortable in. When participants are not able to speak for themselves (e.g., due to dementia or speech and cognitive disorders after a stroke), relatives are invited for an interview. In these cases, due consideration is given to specific ethical issues that may arise regarding informed consent procedures; authorization and advice are sought from the local IRB. Interviews are conducted either in person or online, depending on the participant's preference and context. Depending on the participant's preferences, interviews are recorded as audio or video. Files are transcribed either manually or using GDPR (General Data Protection Regulation) compliant software (HappyScribe 2022), and proofread. Solid data protection protocols are of utmost importance in this phase, as the audio files may contain personal identifiers.

Coding and analysis

In order to determine theoretical saturation (Hennink and Kaiser 2020), the coding and analysis proceed in parallel with data collection. Anonymized transcripts are loaded in computer assisted qualitative data analysis software (Kuckartz and Rädiker 2019; Woolf and Silver 2017), assigned the appropriate variables, and coded. The preferential methodology is thematic analysis, a very flexible method 'for identifying, analysing, and interpreting patterns of meaning ('themes') within qualitative data' (Braun et al. 2018; Braun and Clarke 2012). The approach is hybrid and iterative, with both top-down components (i.e: theory-driven codes, strongly connected with the research question and interview guide) and bottom-up components (i.e: data-driven codes, useful to capture emerging themes). Coding aims to identify, organize, describe, and explain themes emerging in the corpus, coming to a shared interpretation, and identifying opportunities for improving the quality and efficiency of healthcare.

Coding is a collaborative effort due to professional background and language. As the healthcare experiences encompasses medical, psychological, and social factors, a multidisciplinary team can come to a more complete understanding of the corpus. To guarantee intersubjective consistency, every code is complemented by a memo, explaining its exact meaning and its intended use. When theoretical saturation is considered reached, recruitment is stopped, and the coding work is consolidated and finalized.

To ensure that implicit meaning specific to a language are not lost, interviews are coded in the original language. The codes/coding tree remains in the common language of the research team. Particular words and phrases that are difficult to directly translate are highlighted by the researcher fluent in that language, and the cultural significance and meaning in the context of the interview transcript extensively memo-ed. To ensure all researchers have an understanding of the interview and an overview of the corpus of interview material, interview transcripts are translated into the common language using professional translation software. These translations are used only as a reference for the benefit of researchers outside of that language group and are not part of the formal coding and analysis process. Coded segments are translated to English only in the final step of preparing quotes for publication (Ferguson, Pérez-Llantada, and Plo 2011).

The goal is to enable the switch from 'vertical reading' (i.e: traditional reading of the transcripts, line by line) to 'horizontal reading' (i.e: retrieving all the fragments in which the participants talk about specific topics, defined by codes or groups of codes). This is the basis to go beyond individual experiences and understand topics, distilling the 'collective experience' (i.e: the common traits), with an eye to the variations (i.e: the discrepancies). This mapping of themes emerging from the topics, their interplay and their interconnection informs the development of 'OSOPs' (One Sheet of Paper), in which the evidence emerging from the narratives is contextualized, connected, and used to inform ethical reflection, either on specific topics or on the general management of the condition. This approach is based on thematic analysis, which in turn is derived from grounded theory (Ziebland and McPherson 2006).

Dissemination of the results

Once the analysis is finished, the data are prepared for dissemination and future use through a database. Based on the coding structure, the research team defines in the database a module-specific two-level taxonomy, cogent to report and portray the significant aspects of the 'collective experience'. Each taxa is accompanied with a text describing the general lines of the content, again, focussing both on trends and on variations. After completing the creation of the taxonomy, the research team identifies the most relevant coded fragments to attribute to the structure, and creates in the database pseudonymized profiles for the participants from whose interviews the fragments come. The creation of 'experiences' (i.e: selected, curated, and classified fragments in which one interviewee tells a significant portion of their story) knits everything together. Experiences contain a title, a short description, pseudonymized transcript, and (depending on the interviewee's preferences) a link to the original audio or video. Experiences are thus the minimum viable entity of the database, and the database allows to store (and retrieve) them using their ontological properties, classification properties, descriptive properties, or additional metadata. Properties are summarized in figure 3.

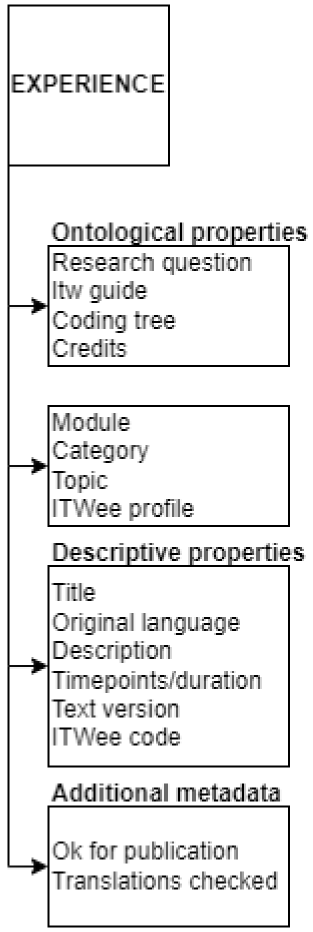

Figure 3, properties of experiences in the DIPEx database

All the content of the database is automatically translated to English, German, French, and Italian, and proofread. The database is a MariaDB system, hosted in the data centre of the University of Zurich, ensuring high data protection standards and adherence to FAIR (findable, accessible, interoperable, reusable) data principles.

Our first completed module contains a total of 334 experiences, belonging to 28 interviewees and taxonomized in 14 categories and 61 topics. The data are fed into the system using a dedicated interface, and can be pulled using anything that supports MySQL queries. This allows multiple data-out interfaces, ranging from multimedia websites (as in the original DIPEx concept) to application programming interfaces (APIs). While the website is mainly intended for lay users, APIs will allow a more specialistic use of the data (e.g: education, training, secondary research); for instance, defining 'meta queries' or allowing bulk download of tabular data. These functions maximise the (re)use potential of the dataset, increasing the value of the entire project, and providing valuable resources for teaching, current, and future research lines.

Modules ready for the public are made available via www.dipex.ch and launched via a symposium including expert patients and healthcare professionals, providing excellent opportunities to present and discuss findings as done in Excellence in patient care in November 2021 (IBME 2021). The website is fully translated into German, French, Italian and English, and constantly reviewed with qualitative and quantitative methods with a view to usability, accessibility, and individual benefit, aiming to fulfil the requirements of the Health On the Net (HON) certificate (HON 2017), to which DIPEx subscribed. Participants can request to have their materials withdrawn from the website at any time.

Quality control and auditing

To ensure consistent quality of our data, alongside the application of the standards recognized by the Equator Network (O'Brien et al. 2014; Tong, Sainsbury, and Craig 2007), we developed a quality control checklist specific to our processes, applied as a self-assessment tool for the researchers working on a module, and as the basis for peer review of the module. Quality control considers every step of the module production. The checklist is provided as supplementary material (appendix 4).

Data protection and data management

Interview data can contain personal sensitive information and are therefore to be treated with utmost care in terms of data protection. To protect our participants' privacy, our process comprises a 2-level informed consent system, and a set of data protection strategies.

Participants are required to sign the first informed consent before recording the interview. Signing this document, they declare they have read and understood the information sheet (appendix 5); that they were given the opportunity to ask questions and clarifications; that they accept the interview to be recorded (in video or audio); and that they consent to the use of the full pseudonymized interview for research and training. The first informed consent is provided as appendix 6.

After transcription and pseudonymization, participants receive a copy of the transcript and a second informed consent form (appendix 7). They can allow the publication of the entire interview, of specific passages only, or completely opt out from publication. Moreover, they can specify if they prefer to make their interview available as video, audio, or text only.

In case we need to send non-pseudonymized interviews to third parties (e.g: for transcription) we use SHA (Secure Hash Algorithm) encrypted containers, and third parties sign a non-disclosure agreement.

Upon data collection, identifiers are decoupled and an individual code is assigned to each participant. Data are stored in a password-protected folder in a server located at the University of Zurich, subject to incremental backup. The file containing the identities and contact details of the participants is SHA encrypted and stored on a different volume.

Data selected for publication are double-checked for complete pseudonymization and saved in the database. The data-in interface has a two-factor multi-user authentication system, allowing granular permission management. Proof-reading can be done either directly via the data-in interface, or exporting and re-importing translation files.

If a participant decides to opt-out from the study and requires data deletion, their code is retrieved, and the material attributed to that code is deleted from the server and from the database. Finally, the participant's entry is deleted from the key file.

Ethics

Any sustainable, future-oriented healthcare system needs to be conceived as a learning system. Learning, of course, requires feedback loops – such as patient experiences. Healthcare systems have been notoriously slow in developing smart ways of systematically and meaningfully taking patient experiences on board. For a long time, data collection has been limited to "patient satisfaction", focusing on items such as food or convenient parking. Patient experiences have evolved conceptually, covering outcome measures relevant to patients, but their collection has remained sketchy in many instances. Narrative data can complement this puzzle in a relevant way: by not imposing topics, approaches such as DIPEx can reveal what genuinely matters to patients, and to what extent patient expectations are met by healthcare services. Listening to patients is indispensable if the goal is patient-oriented care. Translating insights into action is the next step that must follow. Researchers can contribute through the preparation of material (such as trigger films) based on patients' voices that can start interprofessional discussions of opportunities for improvement.

Another imperative regards the dissemination of findings. If participants dedicate their time to research, it is researchers' responsibility as good stewards of the entrusted data to ensure the results are accessible, not only to a narrow community of experts, but also to a broader range of academics and the interested public. Clearly, the use of data and results – particularly if re-identification cannot be excluded – is acceptable only with participants' written informed consent. Interviewees are not to be manipulated into revealing information they do not like to share. Treating participants with respect and heeding the limits they set is an obvious ethical rule that helps avoid exploitation.

Ethical issues may come up when participants reveal delicate information, such as suicidal ideations, drug abuse, or involvement in illegal activities. In such cases, the complex interplay between the interviewer's duty to confidentiality, the participant's right to privacy, and the safety of both is carefully assessed to define a course of action – e.g. putting the participant in contact with organizations or professionals that can offer qualified help.

Another caveat regards the groups and themes that receive scholarly attention. Some groups of patients may seem more attractive from a research point of view, and more promising with a view to citations of future publications. However, from an ethical perspective, all groups of patients should have a chance to be heard, particularly those whose voice might be fainter, such as those who are marginalized, e.g. sans-papiers. At the same time, it is important to acknowledge that reaching these groups is not easy and often requires significant efforts. There is also an attention bias for certain health conditions, which may seem advantageous with a view to recruitment, funding or publication. This should not deter researchers to insist on also covering conditions that are less easy to approach.

Finally, it is a matter of fairness to involve participants rather than just treating them as a data source. We recognize citizen science as a marker of good (open) science, and therefore we try to include participants in every phase of the process, from the definition and testing of the interview guide, to the analysis and interpretation of the results (Participatory Science Academy 2020).

Limitations

Research on patient narratives is powerful and versatile, but it has some important limitations to keep in mind.

The approach we detailed is resource intensive. Researchers in charge of a module need solid training and must be very familiar with each aspect, from sample definition to interview techniques, to qualitative data analysis. While some division of labour is possible, it is inadvisable to split a module in isolated and self-standing work packages. Some aspects can be automated: transcriptions and translations can be produced by software and proof-read by humans; we also automated the production and upload of the clips. This is an important innovation, as manual cutting and upload requires approximately 60 – 70 hours of human labour and about 7 hours of machine time per module, while programmatic cutting and uploading allows to achieve the same results in about 8 hours of machine time. We are currently exploring the possibility to automate (to some extent) also the coding, but it is unclear whether it is possible to achieve a level of quality comparable with human coding (Spitale, Biller-Andorno, and Germani 2022a). In addition, after some years modules might require updates to remain current, adding new interviews and re-conducting the analysis.

This research can be rigorous and systematic. Nevertheless, personal bias can skew the coding and the interpretation. This risk can be mitigated by adopting a shared and multidisciplinary approach, by explaining codes with memos, and by exploring and challenging the preconceptions of the research team. Assessing theoretical saturation is an issue connected to what above. On paper, theoretical saturation is considered reached when no new codes are emerging (Nascimento et al. 2018). In practice, if the coding team didn't approach coding with enough rigour, it could declare theoretical saturation without actually reaching it.

Results from research on patient narratives are particularly vulnerable to 'data torturing'. They make sense when considered in their unity, complexity, and context; in order to build reflections on the entire movie, rather than on a snapshot, hosting a DIPEx project in a research unit natively offering interdisciplinary expertise (such as a biomedical ethics unit) is a good mitigation strategy.

Finally, results must be operationalized and integrated into patient care. This requires a certain predisposition to integrate this evidence on the part of the healthcare system – which currently can depend a lot on personal sensitivities and inclinations.

Conclusion

When compared to other current and emerging collections of patient narratives (e.g: social media pages/groups), the approach we detailed offers significant advantages: conflict of interest is assessed and avoided; data collection and analysis are rigorous and systematic; public-facing content is carefully curated, and the whole process is supported by a lively research community.

A recent systematic review on risks and benefits of patient narratives concluded that 'patient narratives seem to be a promising means to support users in improving their understanding of certain health conditions and possibly to provide emotional support and have an impact on behavioral changes' (Drewniak et al. 2020). This approach goes beyond informing the development of evidence-based PROMs and PREMs, decision aids, or trigger films. Our data structure is built with an eye to the future: curated collections hosted on FAIR databases will provide a fundamental infrastructure for natural language processing approaches to patient narratives, for the training of conversational AIs, for medical education, and for data sharing in the context of international studies.

Finally, this approach can help integrate the contributions of different disciplines sitting at the interdisciplinary table of biomedical ethics – medicine, nursing studies, philosophy, sociology, psychology, anthropology, and others – in the interest of a joint goal: patient-centred care. At the same time, making patients' stories publicly available endorses important cultural changes currently under way, reducing knowledge and power asymmetries between healthcare practitioners and patients (and their relatives), and fostering genuinely personalized healthcare by providing opportunities to listen to what matters to patients.

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8. Future perspectives

Chapter 8, the last work presented in this dissertation, is an attempt to systematize the knowledge and the evidence emerged and generated throughout the whole process of my PhD into a consistent ethical framework, as agnostic as possible (i.e: as compatible as possible) from a metaethical point of view, and as applicable as possible in real life scenarios. The focus is again on risk and crisis communication in the context of public health emergencies, an area which emerged only recently as an interest in ethics. The theoretical approach tries to be simple and elegant, without being simplistic: as communication and understanding cannot possibly be enforced and imposed to the public (in the same way other measures such as quarantine and isolation can be imposed and enforced), the public needs to be fully on board, accepting an open and bidirectional communication; even more so, considering that the public is not a monolithic abstract entity, but a very diverse group of people. Therefore, the polar star of the process is fairness: besides having moral value per se, if the public perceives the process as fair, chances of success are higher. This is how we turn the table, moving from the perceived trade-off between fairness and effectiveness, to fairness as a condition for effectiveness.

The PHERCC matrix. An ethical framework for planning, governing, and evaluating Risk and Crisis Communication in the context of Public Health Emergencies

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Abstract

Risk and crisis communication is a current ethical issue subject to controversy, mainly due to the tension between fairness and effectiveness. In this paper we propose a consistent definition of the risk and crisis communication process in the context of public health emergencies (PHERCC), which comprises six key elements: evidence, initiator, channel, public, message, and feedback. Based on these elements and on a detailed analysis of their role in PHERCC, we present an ethical framework to help design, govern and evaluate PHERCC strategies. The presented framework aims to facilitate risk and crisis communication that is both effective and fair. It comprises five operational ethical principles: openness, transparency, inclusivity, understandability, and privacy. The resulting matrix helps understanding the interplay between the PHERCC process and the principles of the framework, simplifying its implementation with real life examples and scenarios. The paper includes suggestions and recommendations for the implementation of the PHERCC matrix, including the role of censorship and the regulation of free speech; education and empowerment of the public; trust, data access, and contextualization; feedback bias and bias propagation; and reflections revolving around the is-ought issue.

Keywords

Public health ethics; risk and crisis communication; citizen engagement; democratic technologies

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Introduction

Risk and crisis communication

Much has been written on risk and crisis communication; typically, with a 'business-oriented' approach (Quinn 2018), mainly geared toward reputation repair. In this context, communication is aimed at reducing the reputation damage caused by a crisis (Benoit

1997; Coombs 2007; Xu and Li 2013). In 'business-oriented' risk and crisis communication, a crisis is defined as a low-probability event, which occurs unforeseen, and has the potential to generate a vastly negative impact on an organization and on its stakeholders (Burton and Pearson 2016). This definition – and the tradition it stems from – are clearly incomplete and inadequate to understand and define the term 'crisis' as in 'COVID-19 crisis': the pandemic was not a low-probability event (Johnson et al. 2020), there have been similar precedents with other epidemics (Bowen and Heath 2007), its possibility was forecasted (Kreuder Johnson et al. 2015), and its impact did not hit specifically organizations or stakeholders, but the entire world. Some authors developed ethical frameworks for 'business-oriented' risk and crisis communication, suggesting general principles to incorporate in communication strategies. For example, Kim theorizes a model based on transparency (i.e. no information should be kept secret), two-way communication (i.e. listen to how it the message is received), and right time (i.e. such message should be timely) (Y. Kim 2015). Contreras-Pacheco proposes an approach based on care ethics, encompassing five principles geared towards the mitigation of negative outcomes – and reduction of reputational damage – when a business is responsible of a critical event: taking responsibility; apologizing for the pain; acknowledging the victims; honouring the victims' memory; deploying mechanisms to support the victims' families (Contreras-Pacheco 2018).

Maintaining reputation and repairing trust (one of the main aims of the 'business-oriented' approach) is indeed only one component of the communication strategies deployed by local institutions, health ministries, national governments, and by the World Health Organization (WHO) in the context of the COVID-19 pandemic. The main goal was rather providing the public with enough information to elicit protective behaviours and keep people safe: information on the virus' transmission routes; on preventive measures, including the use of hand sanitizers or face masks; and on vaccines as an efficient way to reduce mortality, morbidity and transmission. However, despite some similarities, as the differences between 'business-oriented' risk and crisis communication and 'public health emergencies risk and crisis communication' are significant in terms of aims and process, it follows that these two ethical frameworks are not mutually interchangeable.

This type of communication is better described using the CERC model (Reynolds and Seeger 2005), which represents the systematization and the current gold standard for preparing and organizing the content of risk and crisis communication in the context of public health emergencies. It defines the five common stages of crises: a) precrisis; b) initial event; c) maintenance; d) resolution; and e) evaluation; further, it details what the focus of each phase should be, suggesting specific strategies. These include educating the public and develop consensual plans between the information provider (initiator) and the public as a preparedness strategy; establishing an empathetic communication – although structured and formal— providing information and reducing uncertainty; assessing the public's understanding and dispel fake news; informing about post-disaster clean-up and remediation; evaluating, assessing, and planning for future actions. While the CERC model offers useful guidance for navigating an emergency, it solely focuses on communication strategies, without embedding and analysing the efficacy of this type of communication in an ethical framework – which could ensure justice, intended as fairness, and increase the effectiveness of messages designed through communication strategies as defined by the CERC model.

In this paper, we will refer to the set of communication activities during a public health crisis as 'Public Health Emergency Risk and Crisis Communication'. PHERCC is a crucial process, whose importance is acknowledged and prescribed also by international law, including the International Health Regulations of the World Health Organization, Resolution 46/182 of the United Nations General Assembly, and the Sendai Framework. PHERCC includes the ability to detect, notify and report on public health threats, and disseminate information and recommendations for the population (World Health Organization 2016, 40–41; UN General Assembly 1991). The Sendai framework provides more details on the guiding principles and the aims of PHERCC, specifically in Priority 4, i.e., 'disaster preparedness': to increase communities' resilience to disasters, it is necessary to develop and strengthen people-centred multi-hazard communication mechanisms and social technologies. The aforementioned systems should be developed through a participatory process and tailored to the needs of users, including social and cultural requirements (UN Office for Disaster Risk Reduction 2015, 21).

The combination of recent epi-/pandemics and new technologies that allow rapid and 'horizontal' spread of information (e.g., social media) generated further insight on the strengths and limits of previous and current PHERCC strategies and approaches. In fact, 'public reaction could be considered another outbreak to be controlled during an epidemic' (Hsu et al. 2017). Horizontal means of communication can be both an asset and a barrier – an asset, in that they allow rapid and capillary communication; a barrier, in that they can generate echo chambers, which in turn can foster the spread of rumours and fake news (Malecki, Keating, and Safdar 2020). Moreover, the 'lasting emergency' of COVID-19 has been showing that there is a critical need for theoretical and practical tools to deal with uncertainty and changing evidence, advice, and content of PHERCC:

information providers need to be able to dynamically adapt their messages over time, to different audiences with specific needs and characteristics (Malecki, Keating, and Safdar 2020).

PHERCC is ripe with ethical implications and potential pitfalls (Y. Kim 2015; Attademo 2022). Although some work on the ethics of PHERCC exists (Sellnow and Seeger 2013, chap. 9), a framework that systematizes the issues, the stakeholders, and the approaches, providing both theoretical reflection and practical guidance for planning, governing, and evaluating PHERCC strategies is still missing. As the world wishes to transition, slowly and limping, to a post-pandemic phase, this appears to be the right time to develop a detailed and comprehensive framework for PHERCC, and to incorporate it in the design and development of future response strategies to public health crises.

Conceptualizing the PHERCC process

PHERCC is a multi-actor and multifaceted process. While its core revolves around delivering information to the public, defining the aim of PHERCC is not a simple endeavour. Looking at recent examples emerging during the COVID pandemic, PHERCC aim is to keep people informed and aware of what is happening, to reduce infection rates, to curb economical damage, among many others. These different aims have been achieved by crafting messages concerning hygiene measures, supporting lockdowns, endorsing vaccination uptake, etc. On the one hand, PHERCC aims at eliciting protective behaviours that allow risk reduction; on the other hand, it aims at guaranteeing and fostering freedom of information – as recognized and defined in international law (UN General Assembly 1946; 1948, pt. 19), enabling informed decisions and maintaining public trust in institutions (Loss et al. 2021).

Since the purpose of PHERCC is to deliver information and elicit behaviours, it needs to create a space for an 'asynchronous conversation' between the initiator and the recipients of the action. This entails that a) the initiator needs to understand the identity and characteristics of the public, and the public needs to understand the identity and characteristics of the initiator; b) the initiator gathers all the evidence that can contribute to building an effective and precise message, tailored to the public based on its specific needs; c) the initiator ensures the existence and maintenance of a solid infrastructure through which the conversation with the public can take place; d) defining a set of messages, e) finally, the initiator needs to consider and accept the public's voice and incorporate it as fundamental feedback for the next iterations of communication (Malecki, Keating, and Safdar 2020). In fact, as disasters tend to follow a 'drop loop model', proceeding from baseline to recovery and development through deterioration caused by trigger events, acute crisis, and stabilization (Clarinval and Ahmad 2015), feedback and iterations are core components of the process. PHERCC processes can therefore be described as a looped ladder consisting of six steps: evidence, initiator, channel, public, message, and feedback (Figure 1).

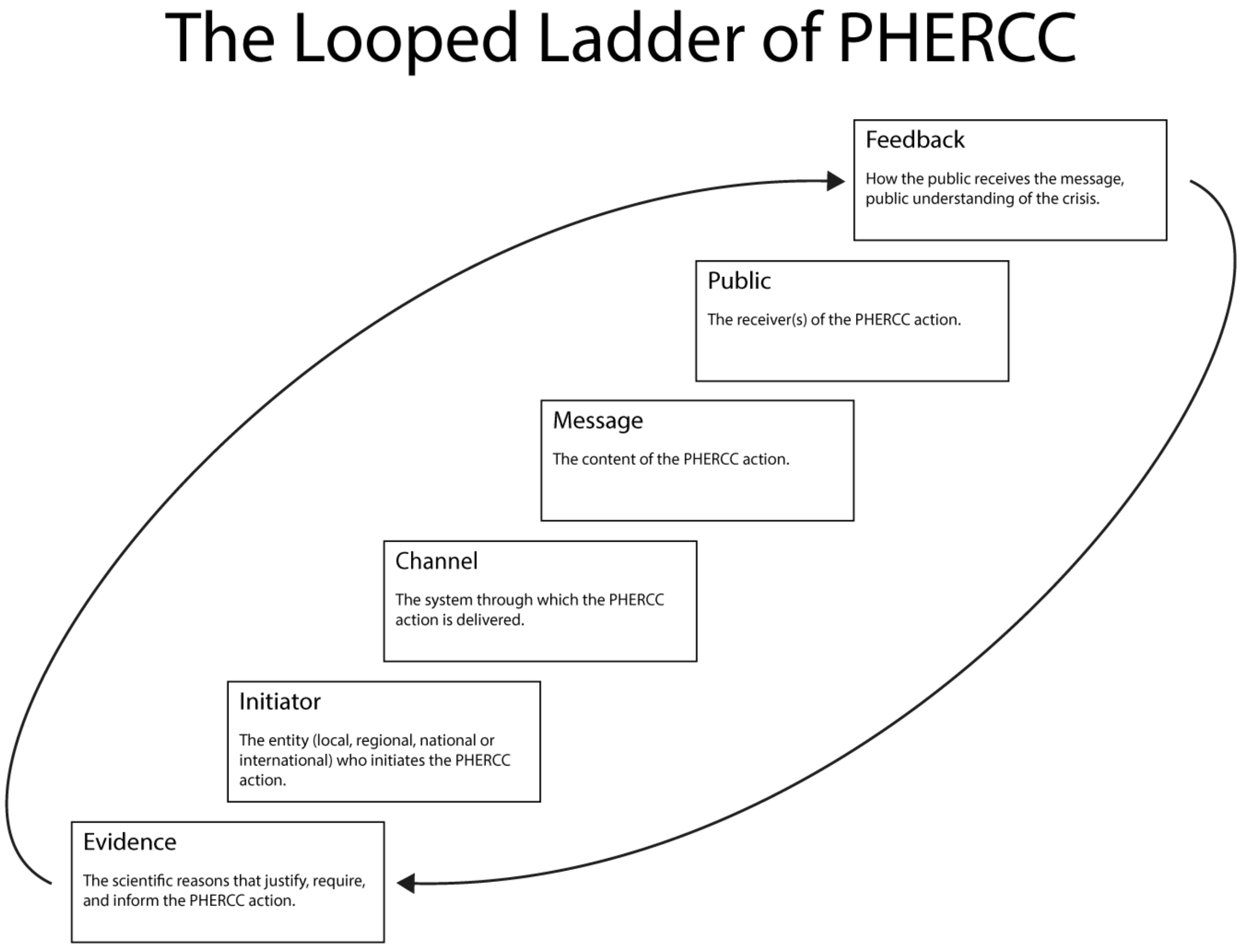


Figure 1. The looped ladder of PHERCC: evidence is used by an initiator to deliver a message to the public through a specific channel that allows feedback to be incorporated as new evidence to craft the next iteration of communication between the initiator and the public.

Evidence

PHERCC needs to be primarily and structurally grounded on scientific evidence (e.g.: how COVID-19 spreads). Conspiracy theories should be debunked whenever evidence is available to do so, and this should play a relevant part in the PHERCC process, as disinformation is harmful and endangers proper public health responses (Love, Blumenberg, and Horowitz 2020). Especially in early communication, when not much evidence on the underlying phenomenon causing a crisis is available, the initiator should ensure no information that is not backed up by evidence is transformed into public health advice to the public. For instance, early pandemic advises from WHO suggested international flights should not be halted as there was no evidence that SARS-CoV-2 could start circulating worldwide (World Health Organization 2020). Later evidence suggesting the airborne nature of COVID-19 demonstrated this advice to be incompatible with a proper pandemic response (Lewis 2022; Zhang et al. 2020): the continuous improvement and growth of evidence needs to be reflected in PHERCC as soon as possible (Ratzan, Sommariva, and Rauh 2020). As mentioned above, feedback is an integral component to build evidence necessary to develop a message, and therefore evidence should also include how the message will possibly be received by the public, and ultimately how the message is perceived by the public. This includes understanding and analysing communication strategies, the instruments adopted to convey a specific message (e.g., social media vs traditional media, which social media channel, textual vs graphical communication, etc.), the timeframe in which the information is provided and the cultural, geographical, and socio-economic context of the public. If compromises regarding complexity need to be made, this needs to go hand in hand with efforts to improve health literacy/numeracy in all groups of society (Ratzan, Sommariva, and Rauh 2020).

Initiator

PHERCC actions are usually initiated by local, regional, national or international authorities, and often in combination, providing a mix of information of local and global relevance. PHERCC initiation requires a reputable and recognized authority, as free as possible from conflict of interest (e.g.: promoting specific protective measures and at the same time holding shares in the companies offering these products or services). The initiator needs to be acknowledged by the public as a leading institution, else the effectiveness of its communication, even when backed up by evidence, would be negatively impacted. This is one reason why the initiator should also ensure its public is responsive and receptive and does not lack trust in the institution providing the information. The establishment of authority occurs when there is no ongoing public health crisis, whereas the reinforcement of institutional trust takes place in a time of crisis.

Channel

Channels are the operative system, or platforms, through which PHERCC actions are delivered – these include official websites, press releases, TV, and social media. The adequacy of the channel is crucial: PHERCC actors tend to be present on established channels as they need to have a sufficiently basin of followers (i.e. receivers of the message), in order to guarantee effective outreach and circulation of messages; however, some communication channels are structurally inadequate for PHERCC actions due to how contents are selected and displayed in the users' feeds (Hindman, Lubin, and Davis 2021), or due to a mismatch between the intentionality of the action and the public's expectation. Indeed, each channel has tailored communication mechanisms and a different public. Specific rules apply to each channel, thus content selection, censorship, and social polarization (i.e., how information is displayed to users based on their own interests) are issues to be considered. Regulations on content selection and transparency of social media are currently being discussed, for instance, in the EU (Satariano 2022), but the road to effective enforcement will be long and complex.

Message

The message is the actual content of the PHERCC action, which is based on evidence, prepared and transmitted by initiators through adequate channels to the public. In line with what discussed above, the same message should be declined in different forms, based on the recipient and the communication channel, maintaining the same meaning and aim, but tailoring it to the needs of the public (SteelFisher et al. 2012; Spitale et al. 2021b). The message is based on evidence produced by scientific literature and the public's feedback. In fact, this evidence should not be limited to the content of the message itself, but also how the message is conveyed. The initiator should ensure the communication strategy is in line with scientific evidence in terms of effectiveness and design, but it should also consider experimenting with different forms to evaluate the efficacy of specific designs and strategies. Indeed, public health emergencies differ from each other, and the public changes its attitude, understanding and predisposition to listen over time, based on unfolding events, as well as changing social, cultural, and economic context.

Public

The public comprises people or institutions for whom a specific PHERCC action is intended, i.e., the receiving end of the messages. Different people understand or misunderstand the same messages in different ways: there is growing evidence that 'social and cultural factors, immediacy, uncertainty, familiarity, personal control, scientific uncertainty, and trust in institutions and media all shape perception and response to risk messaging' (Malecki, Keating, and Safdar 2020). Therefore, a better understanding of the public (intended as a plural, multifaceted, and diverse group) and its specific needs is paramount (Hu 2022).

Feedback

Feedback is a set of information on how different segments of the public receive and understand the message provided by the initiator. Feedback data are crucial for the following iterations of the PHERCC process, especially when facing long lasting emergencies, during which evidence might change as well as the public perception of the underlying issue. A recent and poignant example of this is the so called pandemic fatigue – 'an expected and natural response to a prolonged public health crisis – not least because the severity and scale of the COVID-19 pandemic have called for the implementation of invasive measures with unprecedented impacts on the daily lives of everyone' (WHO Regional Office for Europe 2020). Thus, listening to the public and understanding what they think, and incorporating their feedback in future PHERCC actions plays a pivotal role. Its importance has been previously considered: the Sendai framework explicitly recommends developing people-centred multi-hazard, multisectoral emergency communication mechanisms through participatory processes, tailoring them 'to the needs of users, including social and cultural requirements, in particular gender' (UN Office for Disaster Risk Reduction 2015). Two approaches have emerged: active social listening and passive social listening. Passive approaches entail gathering and studying data, which are shared by people for their own purposes, on social media or messaging platforms. It is an observational approach, based on 'collecting information from digital communities without engaging with them' (Spitale, Biller-Andorno, and Germani 2022b). Active social listening, on the other hand, entails engaging with the public, asking them explicitly their opinions and personal views, e.g., on the implementation of safety measures as well as their acceptability considering their impact on people's lives, businesses, and personal versus societal risk evaluation. Passive social listening systems, although very effective in the short run, can be problematic: their systematic use can undermine the proper functioning of the public health system due to the erosion of public trust in public health institutions (Sekalala et al. 2020). Moreover, passive social listening systems can be used – and have been used – to legitimize discriminatory public health policies against minority groups (Sekalala et al. 2020). Active approaches, on the other hand, although slower and depending on effective bidirectional interfaces between the public and authorities, can help building trust rather than undermining it further (Spitale, Biller-Andorno, and Germani 2022b). A limitation of active social listening approaches, however, is that the collected sample, and thus the opinions, of participants engaged in active discussion is limited and could potentially bias conclusions and determine misunderstanding, creating improper evidence, which could lead to a new iteration of ineffective, or even dangerous, PHERCC actions.

A unifying framework: how it works

Status quo

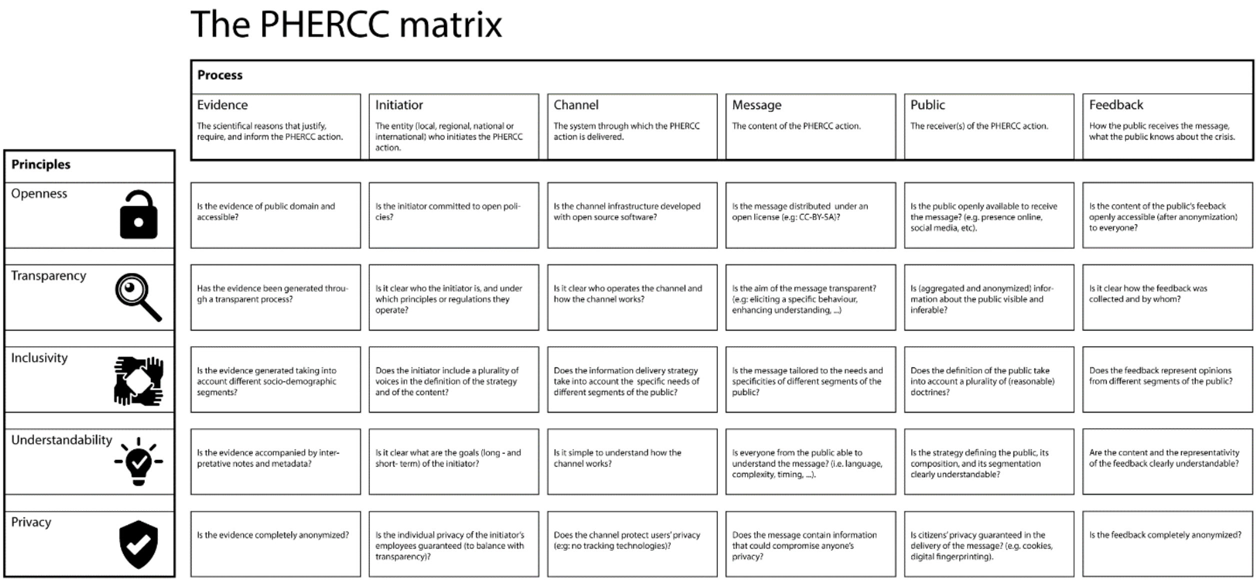
While studying the Chinese response to the 2002 – 2003 SARS outbreak, Bowden and Heath identified 5 key areas: a) a moral obligation to society – 'the level of moral responsibility for an issue is determined by the amount of control the person or organization exercises over the decision'; b) a need for enabling relationships – 'providing candid and accurate information'; c) do no harm and consider harm potential – ground decisions on the moral imperative of respect, not on self-interest; d) maintain legitimacy through ethical actions – being dishonest and not forthcoming information undermines trust and legitimacy; e) the obligation of veracity – 'concealment might indicate a moral problem' (Bowen and Heath 2007). When analysing the impact on human rights of public health surveillance measures in the context of the COVID-19 pandemic, Sekalala and colleagues concluded that 'they should be evidence based, contribute to a comprehensive public health surveillance system, include sunset clauses, be non-discriminatory, and ensure mechanisms for greater transparency and accountability' (Sekalala et al. 2020). Finally, although mostly geared towards developing practical recommendations for communication strategies, the work of Malecki and colleagues provides some insight that is relevant from an ethical point of view. This entails 'data driven transparent decision making'; accepting the public as a partner; transparency, honesty, and acknowledging of uncertainty; compassion and empathy; evaluation and reassessment of the strategy (Malecki, Keating, and Safdar 2020).

Fair or effective?

PHERCC processes, and more generally risk response strategies, are usually considered as requiring trade-offs based on the subtle balance between effectiveness and fairness: a political conception of justice in which 'each person has an equal right to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with a similar scheme for all'. (Rawls 1985). Intended in this sense, fairness includes the respect for individual autonomy. This trade-off could be true – to some degree – for enforceable risk response strategies like quarantine and isolation (Dong et al. 2022; Spitale 2020). However, the case of PHERCC is different, as communication and understanding cannot be enforced. To achieve its aims (i.e., eliciting specific protective behaviours across different segments of the public and increasing risk awareness), PHERCC needs the public to be fully on board. Therefore, in this specific context there is no trade-off between fairness and effectiveness: PHERCC actions will likely fail when they are not perceived as fair by the public.

The PHERCC matrix

Based on the mentioned considerations on justice intended as fairness – as a *conditio sine qua non* to effectiveness – we propose our framework in the shape of a matrix. We defined the PHERCC process, we identified relevant ethical principles, geared toward guaranteeing fairness across the whole process, and we propose the application of said principles in each step. There are two assumptions with meta-ethical relevance in this reasoning. First, supported by some evidence, that there are no trade-offs between effectiveness and fairness; on the contrary, that aiming for fairness can increase the effectiveness of PHERCC actions. Second, in line with Rawls, that fairness is a desideratum in a modern constitutional democracy. In this sense our principles can play both an ethical role – they have intrinsic ethical value – and a pro-ethical role – they are instrumental to the pursuing of aims which have ethical value. Such principles, adopting a principlist view, have intrinsic ethical value; adopting a deontological perspective, they form a stack that contributes to the realization of fairness as a moral duty. Finally, it is important to stress the consistency of the model also from a utilitarian perspective: literature shows that fairness increases the effectiveness of the PHERCC action, producing desirable consequences (Malecki, Keating, and Safdar 2020), therefore the proposed framework has ethical value also from a utilitarian perspective. Thus, a systematic application of this framework in the planning, governing, and evaluation of PHERCC actions can be understood as an enabling factor for a fair and effective intervention, and – importantly – for a fair and effective public discourse. Our matrix is summarized in Figure 2.



The PHERCC matrix

	Process					
	Evidence	Initiatior	Channel	Message	Public	Feedback
Principles	The scientifical reasons that justify, require, and inform the PHERCC action.	The entity (local, regional, national or international) who initiates the PHERCC action.	The system through which the PHERCC action is delivered.	The content of the PHERCC action.	The receiver(s) of the PHERCC action.	How the public receives the message, what the public knows about the crisis.
Openness	Is the evidence of public domain and accessible?	Is the initiator committed to open policies?	Is the channel infrastructure developed with open source software?	Is the message distributed under an open license (e.g: CC-BY-SA)?	Is the public openly available to receive the message? (e.g. presence online, social media, etc).	Is the content of the public's feeback openly accessible (after anonymization) to everyone?
Transparency	Has the evidence been generated through a transparent process?	Is it clear who the initiator is, and under which principles or regulations they operate?	Is it clear who operates the channel and how the channel works?	Is the aim of the message transparent? (e.g: eliciting a specific behaviour, enhancing understanding, ...)	Is (aggregated and anonymized) information about the public visible and inferable?	Is it clear how the feedback was collected and by whom?
Inclusivity	Is the evidence generated taking into account different socio-demographic segments?	Does the initiator include a plurality of voices in the definition of the strategy and of the content?	Does the information delivery strategy take into account the specific needs of different segments of the public?	Is the message tailored to the needs and specificities of different segments of the public?	Does the definition of the public take into account a plurality of (reasonable) doctrines?	Does the feedback represent opinions from different segments of the public?
Understandability	Is the evidence accompanied by interpretative notes and metadata?	Is it clear what are the goals (long - and short- term) of the initiator?	Is it simple to understand how the channel works?	Is everyone from the public able to understand the message? (i.e. language, complexity, timing, ...).	Is the strategy defining the public, its composition, and its segmentation clearly understandable?	Are the content and the representativity of the feedback clearly understandable?
Privacy	Is the evidence completely anonymized?	Is the individual privacy of the initiator's employees guaranteed (to balance with transparency)?	Does the channel protect users' privacy (e.g: no tracking technologies)?	Does the message contain information that could compromise anyone's privacy?	Is citizens' privacy guaranteed in the delivery of the message? (e.g. cookies, digital fingerprinting).	Is the feedback completely anonymized?

Figure 2. The PHERCC ethics matrix: the first row describes the PHERCC process, the first column describes the principles, the intersections describe the application of the principle in the different steps of the process. As PHERCC processes are context-specific, the questions are intended to be representative and not exhaustive of the interplay between the process and the principles.

Openness

Openness in PHERCC is conceptualized similarly to the concept of openness in 'open science'. The Draft Recommendation on Open Science produced by the UNESCO General Conference defines it as 'an inclusive construct […] aiming to make multilingual scientific knowledge openly available, accessible and reusable for everyone, to increase scientific collaborations and sharing of information for the benefits of science and society, and to open the processes of scientific knowledge creation, evaluation and communication to societal actors beyond the traditional scientific community' (UNESCO General Conference 2021). From a theoretical point of view, 'openness' can be understood in two ways: first, as the sheer availability of information, be it datasets resulting from primary research, or code; second, as the attitude and ability to create new knowledge, the will to share it and the ability to receive it.

Transparency

According to Turilli and Floridi, information transparency is not an ethical principle per se, but rather a 'pro-ethical condition', in that it enables an ethical evaluation of the information, which per se could be considered ethically neutral (Turilli and Floridi 2009). In the context of PHERCC, information cannot be considered ethically neutral, as it allows participation and informed decision making, fostering autonomy. Therefore, transparency can be considered as a full-fledged ethical principle. Transparency is intertwined with openness, as they are mutually enhancing (Ball 2009). Michener and Bersch developed a solid framework for transparency, identifying two hallmarks: 'visibility of information, and its inferability – the ability to draw accurate conclusions from it' (Michener and Bersch 2013). Transparency and openness play, together, a relevant role in determining the accuracy, and thus fairness, of information. Disinformation is produced with a willing act to deceive, and therefore disinformation per se can involve openness but not transparency, as the aim of the message is hidden and not conveyed together with the message itself. Misinformation, instead, is false information which has not been necessarily shared or produced with the intent of deceiving, and thus meets the principle of transparency but not that of openness, since openness requires the ability to understand and elaborate on a piece of information.

Inclusivity

In line with Rawls, reasonable pluralism is a basic feature of liberal democracies. It entails the societal co-existence of 'a plurality of conflicting reasonable comprehensive doctrines, religious, philosophical, and moral'. Liberal democracies must avoid 'friend or foe' approaches to conflicting doctrines – as long as they are not incompatible with the very idea of a constitutional democratic regime (Rawls 2005b, 441). Intended in this sense, inclusivity plays a central role in the PHERCC framework. For these reasons, information should be as effective as possible for as many people as possible, including minorities. In the same way, everyone should have the ability to talk back to the system, being actively engaged and having the possibility to partake the public discourse. PHERCC, for example, should include strategies to deal with people lacking access to Internet, or people with no understanding of the initiator's preferred language of communication. Also, inclusive approaches should attempt to ensure information won't be polarized, and ideally use communication strategies that attempt to bypass biases produced by polarized channels of communication. For example, more transparency on knowledge gaps at the beginning of the COVID-19 pandemic and a communication strategy focused on the effectiveness of masks to prevent the spread of SARS-CoV-2, without promoting their use or accusing those opposing their use to endanger the population at large, could have mitigated political categorization on social media of the masked versus unmasked debate during the COVID-19 pandemic.

Understandability

The principle of understandability further broadens the scope of inclusivity. PHERCC actions should consider that the recipients of information are coming from different socio-cultural backgrounds, hence they not only have different world views, but also different levels of education and different predisposition to understand specific concepts with a specific communication strategy and in a specific timeframe. Understandability is a matter of 'fair opportunity' – which guarantees everyone the possibility to be part of the PHERCC conversation, and the application of this principle helps delivering a more capillary message, enhancing its penetration. The role of the public in shaping the initiator's ability to produce an effective message has been discussed before – as such, understandability should be a guiding principle to shape actions, and in particular the type of communication adopted for a specific goal. Implicitly the public, with its diversity, provides a variety of voices that should be used to generate more messages, reaching out to more people. The initiator is generally a trusted institution with experts in public health, and thus should provide guidance and leadership in PHERCC. This requires the involvement of the public, its plurality and understanding of communication not only as the receivers of the message, but also as those shaping the message: a) through the feedback mechanisms described in the PHERCC matrix, and b) by deploying influencers as initiators themselves – with their own ability to reach out to specific niches and with a specific, already existing, and perfectly tailored communication system.

Privacy

Privacy is a fundamental human right, based on the assumption that everybody should enjoy a free space for 'development, interaction and liberty, a "private sphere" with or without interaction with others, free from State intervention and from excessive unsolicited intervention by other uninvited individuals' (UN High Commissioner for Human Rights 2018). Our understanding of 'privacy' must be broadened by the enlargement of digital horizons, and the growth of digital footprints: 'the right to privacy is not only impacted by the examination or use of information about a person by a human or an algorithm. Even the mere generation and collection of data relating to a person's identity, family or life already affects the right to privacy, as through those steps an individual loses some control over information that could put his or her privacy at risk' (UN High Commissioner for Human Rights 2018). Interference with people's privacy is possibly justified only if two conditions are met: the interference is not arbitrary, and it is defined by the law (scope, extent, duration).

Discussion

Suggestions for implementation

PHERCC is a multi-actor process. It involves research institutions generating evidence; local, regional, national or international initiators; software engineers and media experts developing or improving communication channels; copy strategist, copywriters, graphic designers and translators transforming evidence-based recommendations into segmented messages; the public itself, as a co-actor providing feedback in the form of evidence, and supporting the role of the initiator in shaping PHERCC; and again, research institutions processing the feedback and developing further contributions to the evidence-based process. The implementation of the framework is simple, but not straightforward. It requires everyone involved in the process to be aware of the general aim of PHERCC, of the specificities of the step they oversee, and of the ethical values that should help shaping it. This stands true for the planning of an action, for its governing, and for its evaluation. In this sense, the initiator can assume a pro-active role, as a 'primus inter pares', ensuring that the various co-actors are aware of and apply the principles to the step they are involved in. This entails education and training actions – i.e. empowerment, to be conceived as a structural part of disaster preparedness – as recommended by the Sendai framework (UN Office for Disaster Risk Reduction 2015).

Strengths and opportunities

Openness and transparency through the process foster trust and allow independent third-party verifications or audits. Adopting inclusive approaches, which consider understandability, allows the design of better tools, strategies, and messages. This in turn allows people to effectively perceive themselves as co-actors, rather than as the recipients only – once more, fostering trust and adherence to evidence-based policies to address a public health emergency. Privacy, clear data processes, and data management by reputable, open, transparent, and trustworthy institutions put people in the condition to freely express their opinions, even when they are very critical – and thus important to consider when aiming for fairness and effectiveness.

Adopting this framework offers several opportunities. People can be provided with information, which is not only relevant, precise, and timely, but also personalized, based on their individual needs, understanding of the ongoing crisis, and their reactions to current or future measures to address the emergency. Such information should be simple to understand, and geared towards eliciting specific protective behaviours, in a way which is perceived as non-judgemental – especially on morally loaded topics. We propose a paradigm shift – from policy-makers 'teaching the public' with a (limited and failing) paternalistic approach, towards fully acknowledging the public as a co-actor of the process.

During the COVID-19 pandemic we could witness the explosion of an arms race in info wars: misinformation rampaged, both on mainstream and on new emerging channels (Cuan-Baltazar et al. 2020); consequently, efforts to track, debunk and contain such misinformation rampaged as well. Adopting the PHERCC framework and incorporating its principles in the definition of the actions can help avoiding or at least curbing this issue.

Which issues can this framework address?

Censorship

In a crisis such as the ongoing COVID-19 pandemic, initial assessment of scientific evidence shaping messages and public health policies is typically performed in an environment that was unprepared and in a context with lack of information. In this information void, disinformation and conspiracy theories can emerge at a quick pace, especially if guidance is not promptly provided to the public and to policy-makers. In a short timeframe and in an unprepared environment, curbing misinformation is difficult and likely relies on stronger measures – in the case of the COVID-19 pandemic we have seen limitations of personal freedoms in the form of lockdowns, and for misinformation we have seen attempt to censor potentially harmful information. Censorship is a double-edged sword which can save lives in the short term, but can impact trust in those institutions (i.e., the initiator) providing information (Niemiec 2020). Thus, over time and when a crisis is not resolved in a short period of time, censorship can allow a spiral formation and reinforcement of conspiratorial behaviours, which can damage the societal fabric and have a negative impact on the expected effects of policies aimed at addressing the emergency (Chang et al. 2022). Censorship of information can be compared to lockdown measures to reduce the spread of a virus – they are effective but short lived. Our framework considers an active role of the public in shaping evidence, thus acting as co-actors in a process of information production. The involvement of the public in the PHERCC process can have positive consequences in the medium and long-term, thus creating an environment which discourages the spread of misinformation. This approach can be compared to mass vaccinations that equip the public with resilience against disinformation and conspiracy theories. Besides, the effectiveness of our PHERCC framework is enhanced when the public is resilient to misinformation ahead of a crisis. Preparedness requires educational measures and research to understand and identify the best tools and teaching strategies to build resilience. This would allow, with the emergence of a new public health crisis, a reduced necessity to impose measures and a higher involvement of the public as a co-actor from an early stage of the crisis.

Public health crises can further exacerbate political and societal tensions within democratic societies. Therefore, PHERCC and the potential use of censorship to deal with misinformation can have larger effects on society than those such messages and censorship are designed for. For example, the use and abuse of censorship can lead to public surveillance, attempts to identify citizens with "deviant" opinions, as well as the generation of predictive modelling as a first step towards controlling the population. In fact, most conspiracy theories emerged during the COVID-19 pandemic have something to do with the idea that a political elite is controlling or attempting to control people's behaviours (Germani and Biller-Andorno 2021b). Examples include: that vaccines are implanted chips controlled by 5G technology, or that vaccines are tools to control the increasing population size, etc. (Spitale, Biller-Andorno, and Germani 2022b). These "Brave new world" scenarios emerge as potential derangements of actual risks stemming from the use of censorship, especially when used for a prolonged period.

Convincing versus building: top-down vs bottom-up approaches to information

Providing information can follow two distinct paths, one coming from an initiator and directed to the public, and another, as proposed in our framework, directed from the initiator with an active feedback role provided by the public, and directed to both the public and the initiator. The second approach, which is a bottom-up approach, is preferrable according to our PHERCC framework. If the process of evidence creation and knowledge formation is shared between initiator and the public, and if the latter perceives it is playing a role in such process, then knowledge will be perceived as shared and not imposed, and we could classify this as a top-down approach. This is relevant, as it may help reducing misinformation and debunking conspiracy theories. Therefore, the information provided should build knowledge and evidence, rather than just convincing the public to adopt a certain behaviour. Drawing an example from the COVID-19 pandemic, masks can effectively reduce the spread of SARS-CoV-2 (Howard et al. 2021); there are two approaches to inform the public: a) convincing them that evidence exists to claim masks are effective – this is a convincing effort shaped as a top-down approach to information; b) explaining how viral transmission occurs, and listening to what the public would want to do, once they have such understanding, to curb down viral transmission – this is a bottom-up approach to information.

Trust

As discussed in the introduction, risk and crisis communication has been typically studied and understood with a 'business-oriented approach', i.e., the company or organization uses a set of strategies to deal with the negative impact caused by an unforeseen event. As we discussed, the role of PHERCC goes beyond that, but nonetheless we can consider some relevant aspects based on a 'business-oriented approach' and our PHERCC framework. The initiator of a PHERCC process (e.g., WHO) has the role, according to our framework, to integrate the public's feedback in the evidence-building process necessary to shape messages directed to policy-makers and to the general public.

As discussed, failing to integrate the public would mean adopting top-down approaches to inform the public, which can create a distance between initiator and public, and break the loop of information creation and sharing in the PHERCC process. Such distance reflects on public trust in the institution providing the information, thus creating a negative environment in which the initiator is compared to an elite controlling information and shadowing opposing worldviews, understandings (and misunderstandings) of the crisis. The initiator, to maintain high public trust, should therefore a) involve the public as a co-actor, as previously explained; b) consider that its role as information provider should involve branding and advertising itself, as a business-oriented institution would attempt to do, depicting itself as a service providing value to the public, and not just to themselves: the public needs to 'buy the product' (i.e.: the message) and provide feedback on how to make such product more effective, understandable and inclusive.

Open issues, limitations, and ways forward

Regulating information and free speech

The debate over free speech on social media is relevant in this discussion and is particularly timely. The rise of misinformation on social media has posed great risks to people's lives during the COVID-19 pandemic. Thus, measures including censorship were taken by social media including Facebook and Twitter, in line with guidelines provided by WHO (Mosseri 2017; Twitter 2021). Recent debate on Twitter's policies and free speech initiated by Elon Musk is embedded in the debate about how PHERCC should be handled – and about how information should be handled in general. Two opposing worldviews address the issue from different perspectives: a) a regulatory (censoring) approach, sees information (i.e., misinformation) as a potential weapon, whereas purists' free speech views, including Musk's, see regulating misinformation as an assault on free speech, with the consequences of fostering mistrust and further conspiracies (Musk 2022b; 2022a). Our framework addresses how resilience-building methods should be preferred, as reliance to misinformation bypass the problem of regulating information and the implication for free speech. However, our framework relies on educational and training measures, which haven't been identified yet, as tools to build resilience and thus increase preparedness in the event of a new public health crisis requiring PHERCC.

Education

Education/teaching measures to build the public's resilience to misinformation is fundamental in the emerging phases of a public health crisis, especially when evidence-based information is not readily available as the underlying cause of the crisis is not yet fully understood. In this context, information voids are usually filled by ill-founded conspiracy theories and misinformation, unless the public is already 'vaccinated', i.e., resilient, to these dynamics. Our framework theorizes that such voids could be filled by designing simple and effective education strategies, which are ideally inclusive and not costly, understandable, and not time consuming. So far, we identify two major limitations to this approach: 1) there is no substantial evidence on what skills should be taught to build information literacy (Albitz 2007), and 2) there is no understanding of which education plan, strategy and design would be effective in building such skills (Willingham 2020). Such limitations will need to be addressed by research institutions as quickly as possible, as the understanding of these aspects may have a relevant impact on the PHERCC process and the functioning of the proposed framework once the next public health emergency arises.

Data access and contextualization

Openness is a core principle in the proposed PHERCC matrix. As explained, this implies that data should be available to initiator and public alike. One issue is that, without public resilience to misinformation and with limited instruments to understand and read publicly available data, such undigested pieces of information can be freely misinterpreted or can be manipulated to fill information voids, thus having a negative effect on the PHERCC process. Educational approaches will also need to provide tools to make publicly available data understandable without restricting access to them.

Feedback bias and propagation

As proposed, the public should participate in the PHERCC process not only as recipient of a message, but also as co-actor in building evidence to generate new messages. The role of the initiator, as specified, is to provide guidance and leadership in the process, but integrating public feedback into an effective action has the risk of propagating the initiator's bias towards evidence and the evidence received through public feedback. For example, the public may report to the initiator the need to discuss the role and differences played by traditional vaccines versus mRNA vaccines, as the public seem to be concerned that mRNA vaccines could alter DNA. The initiator could then attempt to explain how mRNA vaccines work and why they do not alter DNA – however this message can be read and understood by some as an attempt to defend the roll-out of vaccines despite lacking evidence to protect the interest of pharmaceutical companies. To prevent these misunderstandings, we propose that the initiator investigates the potential effects of a given action on a public sample, who reports their feedback actively – thus, again, allowing the public to use active social listening systems to participate in the PHERCC process as co-actor. Such feedback would provide immense value and understanding of how a certain message, its wording, design, and adopted communication channel could lead to a desired or undesired effect.

The 'Boaty Mc Boatface' problem and the is-ought issue

In March 2016 the United Kingdom's Natural Environment Research Council (NERC) launched an online poll to find a name for a new, big, and expensive polar research ship. Everyone from the public could participate, suggesting a name or voting for one of the suggestions. The results were clear: NERC's new jewel, 15,000 tons and 129 metres of might, would have been called… 'Boaty Mc Boatface'. NERC was clearly hoping for something different, more highbrow and less prankish – in fact, they overruled the public's decision and chose a more sober solution, opting for 'RSS Sir David Attenborough' (NERC 2016). The winning crowdsourced name, 'Boaty Mc Boatface', lives on in two ways: as the name of one of the ship's autonomous submersibles, and as a memento: when you let people decide about something, you might have disappointing results. This same phenomenon, which makes Boaty Mc Boatface's story such a good joke, might have tragic outcomes in the PHERCC context. What if through the feedback loop of a PHERCC action we see that the public is strongly in favour of actions that are morally unjustifiable, such as killing all the infected people, or denying treatment to minorities on the base of vaccine status or of racial arguments, the elderly, or people with pre-existing conditions? And what if, despite all evidence provided, there is a strong preference for mitigation measures that do not have any scientific backing, such as stocking hydroxychloroquine rather than vaccines for COVID-19? This is just a special case of Hume's is-ought problem – i.e.: we cannot derive prescriptive conclusions from descriptive premises. MacIntyre proposed a solution based on the notion of telos: 'human beings […] have a specific nature; and that nature is such that they have certain aims and goals, such that they move by nature towards a specific telos'. Good is therefore whatever allows to pursue that aim, hence it is possible to ground moral judgement on facts (MacIntyre 2007, 148–50). It is not our intention to delve into metaethics with this work, which in that respect aims to be as agnostic as possible. But this issue, one of the fundamental struggles of empirical ethics, cannot be ignored. In this sense, it is important to keep in mind that we propose to incorporate the public in a multi-actor discourse, which is not the same as 'letting people decide what to do'. Long-term empowerment strategies, as detailed before, will mitigate the risk of incurring in Boaty McBoatface scenarios. But reality and contingency will call for flexibility in the implementation of the framework.

Conclusion

Although we started to probe feasibility and explore the implementation of this approach in different settings, ranging from Switzerland to Hong Kong and Singapore, much more research in this novel area is needed: PHERCC is a complex, multifaceted, and multi-actor process, and a crucial component of risk preparedness strategies. As the COVID-19 pandemic demonstrated, PHERCC is dense of ethical implications and potential pitfalls. A common misconception is to perceive that PHERCC actions require a trade-off between justice – intended as fairness – and effectiveness: while this can be true for other risk control measures, those which can be enforced, this is not true for communication and understanding – which cannot be enforced by any means. We therefore identify fairness as the main driving moral value of PHERCC actions, and propose a framework encompassing five principles: openness, transparency, inclusivity, understandability, and privacy. The matrix we propose can help planning, governing, and evaluating PHERCC actions, incorporating these principles across the board. A consistent implementation of the PHERCC matrix, keeping into account its strengths and limitations, fosters societal resilience by strengthening democracies. Finally, it can help to develop and bolster people-centred multi-hazard communication mechanisms and social technologies that are both fair and effective, in accordance with the recommendations of the United Nations Sendai Framework for Disaster Risk Reduction.

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9. Conclusion

This work started as an emergency response, as a way to be of some use to society during the COVID-19 crisis, rather than sitting at the window and watching what was going on, minding my own business. Therefore, it began as well-meant as disorganized. Organization emerged over time, and now, after two years and a half in the pandemic, that structure is finally clear. Across these papers we confronted with the limitation of personal freedom, the very first issue that the pandemic brought us. We then developed new NLP-based instruments to keep the pace with a rapid evolving phenomenon, instruments that have already proved useful in other situations and fields, and that will keep serving the scholarly community over the next years. We have identified and characterized the 'big five', i.e. what we consider the most pressing ethical issues presented by the pandemic. Again, the same approach and the same methodology, a combination of philosophical analysis and distant reading, can (and will) be used to re-generate the same analysis in a near future – which would be interesting for comparative purposes – or translated to other contexts and other topics. We have engaged deeply with risk and crisis communication, characterizing active and passive social listening, developing approaches, software and reflections that can improve how we deal with both. We have described a state-of-the-art method to collect and incorporate voices of patients (in the form of narrative interviews) in an evidence base which is a great source of wisdom and insight for an informed and people-centric evidence-based ethics. Finally, resulting from the experience and from the data gathered in the process, read in light of the epistemological approach declared in the introduction, we have developed a theoretical framework for the ethics of risk and crisis communication. It is an ambitious feat, keeping in mind that we aimed for theoretical solidity, straightforward applicability to real-life scenarios, and to metaethical agnosticism. I think it worked.

This is a conclusion, but this work is far from being finished. COVID-19 was a lesson, one which brutally unveiled the fragility of our societies, and their lack of preparation to face global threats and radical changes in our lifestyle. And, at the risk of sharing the fate of the famous inductivist turkey, it's quite likely that COVID-19 will not be the last global threat we will have to face during the time of our lives. As you see the solidity of an (ethical) system when you stretch it to the limits, what an amazing time to be an ethicist. This work's aim is therefore to pave the way, and to set a direction giving an example: this is what and how the academic community can contribute – and wants to contribute – to the wellbeing of the society it stems from: mapping, understanding, and building systemic resilience. Not from up high, inside the ivory tower, but from down here, on the dirt we share. Not alone, imposing some sort of exoteric knowledge to a society of unaware peasants, but in a dialogue between peers. Not keeping our knowledge, our methods, and our data secret and well locked in some remote vault, but cracking everything open – for everyone. That's why every bit (literally) of this path is open (open data, open access, open source, …) – and as much as possible, inclusive. It's not (only) about my punk attitude to science. It's about fairness, which is a value per se, and often also a door to effectiveness.

I have always cultivated a very deflationist notion of good in ethics (borrowing 'deflationist' from 'deflationist notion of truth in logic' – thanks Tarski), trying to remember that in most cases we cannot do 'good', but in very special cases, when we are lucky and the stars align, we can do 'least possible bad'. This time is different, as for the first time in a while I have the feeling I'm onto something good for real.

There will be future work, already planned, resulting from this. We intend to pursue further this weird idea of empowering people, guaranteeing everyone the means to participate in a reasonable public discourse which requires some command of key moral terms, such as 'fairness' or 'solidarity'. It will take weird, unusual shapes, unfamiliar and novel to the academic world: a graphic novel, for instance, and a game. That's the beauty of a horizontal and open approach to knowledge – you talk to people, listen to what they want, infer what they might need, and you end up somewhere new and marvellous.

Oplà it's done – as in the preface, I hope it was good fun.

10. Other works

This is a short list of other funny little things I've worked on during my PhD, that for different reasons I decided not to include in the dissertation (e.g: topic, length, nobody likes to read thousands of lines of code, …).

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12. Appendices

Appendix 1. Ethical issues of COVID-19 – the emerging Big Five – Search strategies used for the characterization of the 'big five' (Chapter 4)

1. The role of autonomy, rights and freedom in a pandemic

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR "SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (autonomy[TiAb] OR rights[TiAb] OR freedom[TiAb])

2. Privacy vs. efficient and effective pandemic management

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR "SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (privacy[TiAb])

3. Equity, fairness and solidarity under conditions of resource scarcity

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR "SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (equity[TiAb] OR fairness[TiAb] OR solidarity[TiAb] OR "resource allocation"[TiAb])

4. Proportionality of measures: legitimation and procedures

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR

"SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (proportionality[TiAb])

5. Trust and trustworthiness

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR "SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (trust[TiAb] OR trustworthiness[TiAb])

Appendix 2. The anti-Green Pass rhetoric in Italy is shaped by anti-vaccine views and focuses on limitations of personal freedom: A social listening analysis on Telegram chats. Supplementary material: original text in Italian (Chapter 6)

Green pass and vaccines

> *Sul vaccino invece è un grave errore prendere posizione. Chi lo vuole fare lo faccia. Il punto è solo essere contrari a questa limitazione di libertà e molti vaccinati sono contrari al green pass. Non introducete elementi divisivi o di estremismo che votano al fallimento l'iniziativa (university, south, Pos. 742)*

> *come si può ignorare la questione vaccino se è letteralmente l'opzione principale che permette di ottenere un pass? (university, north, Pos. 6693)*

> *Sono contrario al green pass perché lo vedo uno strumento coercitivo e ipocrita messo in atto dal governo in quanto esso, se vedesse nel vaccino una strada sicura da seguire dovrebbe avere la coerenza di renderlo obbligatorio e invece non si prende la briga di farlo (university, south, Pos. 1807)*

> *il greenpass è un modo per raggirare l'obbligatorietà che non può essere messa. Il Green pass è un "incentivo" detto molto soft, ma di fatto appunto un obbligo messo a tavolino. (university, center, Pos. 14716 – 14718)*

Dalla letteratura scientifica risulta sempre più chiaramente che: 1) Esistono cure molto efficaci oer il Covid che indicano che i vaccini non sono affatto indispensabili. 2) i vaccini hanno spesso gravi effetti collaterali a breve, medio, e a lungo termine, esiste il fondato timore che potrebbero indurre gravi patologie (tumori, malattie autoimmunitarie e degenerative, sterilità…) e sono tutt'ora in piena fase sperimentale. 3) i vaccini facilitano lo sviluppo di varianti, molte delle quali particolarmente virulente, e non andrebbero eseguiti in fase epidemica e tantomeno pandemica. 4) i vaccini non proteggono in modo assoluto dal Covid come viene detto, ovvero i vaccinati si possono infettare e possono a loro volta contagiare… per cui non dovrebbero avere il Green pass se non facendo anche loro il tampone… (university, center, Pos. 3572 – 3579

chi mi garantisce che a causa della somministrazione del vaccino io non abbia degli effetti gravi che potrebbero ledere il mio futuro? Chi mi risarcirebbe di eventuali danni? (university, north, Pos. 25293-25294)

Le statistiche evidenziano che il numero dei morti per Covid e' uguale a quello dei morti da vaccino soltanto che il numero dei morti per Covid e' di molto sovrastimato (il numero comprende anche i decessi per altre cause ma catalogati come Covid poiche' tampone positivi) mentre i morti da vaccino (senza parlare dei casi di effetti avversi gravi) sono molto sottostimati in quanto viene fatta poco e male solo la vigilanza passiva. (university, center, Pos. 15682 – 15688)

Bisogna ribellarsi, questo vaccino é una terapia genica senza alcuna garanzia di funzionamento. I vaccinati sono infettivi come i non vaccinati, é evidente che questo vaccino non protegge dal COVID. (university, north, Pos. 2612)

É scritto in tutti i documenti ufficiali delle case farmaceutiche e dell'OMS che non c'é alcuna evidenza che la vaccinazione fermerá la diffusione del virus (university, north, Pos. 3385)

Sovrappopolazione, c'è lo dicono da anni, ed il vax secondo me serve a risolvere quel problema altro che covid… (university, south, Pos. 2343)

Il loro obiettivo è arrivare alla manipolazione dell'essere umano iniettando in questo un siero che contiene grafene che poi con certe frequenze può *reagire e modificare il comportamento delle cellule. Modificando il comportento delle cellule puoi modificare quello dell'essere umano (generic, Pos. 72471)*

Beyond vaccines: Green pass, legal aspects and personal freedom

È EVIDENTE CHE IL GREEN PASS È UNO STRUMENTO DI DISCRIMINAZIONE POLITICA CHE NON HA ALCUNA RELAZIONE CON L'EFFETTIVO STATO DI SALUTE… (university, center, Pos. ***3572 – 3579)***

Il green pass è palesemente incostituzionale e di natura discriminatorio ed è esclusivamente politico dato che non ha alcuna base scientifica visto che il rapporto prima enunciato è molto chiaro a riguardo,poi non lo rendono obbligatorio per legge altrimenti sarebbero obbligati a risarcire i morti per il vaccino. (university, center, Pos. 7520 – 7522)

Non avete ancora realizzato che se anche il Regime deciderà di ritirare il COVID PASS, di farvi tornare a lavorare, siete comunque già diventati cittadini di un Regime totalitario? Cittadini di uno schifosissimo Regime basato sulla menzogna, sulla pogressiva eliminazione delle libertà, sulla soppressione violenta del dissenso? (generic, Pos. 2127)

il "green pass non può essere richiesto poiché discriminatorio, lesivo della privacy e viola i seguenti articoli di Legge: - Art. 187 del Regolamento TULPS: un esercente commerciale è obbligato ad accogliere nel proprio esercizio qualsiasi persona, senza discriminazione pena ammenda fino a €3000,00.- Legge sulla Privacy: nessuno può obbligarci a fornire informazioni sulle nostre condizioni di salute.- Art. 120 Costituzione italiana: nessuno può limitare la libertà di movimento dell'individuo nel territorio della repubblica italiana. - Art. 13 Costituzione italiana: nessuno può limitare la libertà personale senza che ci sia una disposizione dell'Autorità Giudiziaria su fatti che riguardano il singolo individuo. (generic, Pos. 3448)

Aggiungi che rispetteremo tutte le misure di sicurezza anti covid (distanziamento sociale ,igienizzazione,mascherina). Per quanto riguarda il riferimento a leggi e trattati,non vogliamo citare la convenzione dei diritti umani,il trattato di Oviedo e la sentenza della Cassazione che afferma che la salute del singolo non può essere sacrificata per la salute collettiva?non *vogliamo accennare al principio di autodeterminazione? (university, center, Pos. 395 – 397)*

Guarda al social score system cinese per capire la direzione folle di queste azioni, tipiche di sistemi dittatoriali e non di democrazie avanzate (university, south, Pos. 3755)

Oramai io credo che sta gente sia lobotomizzata e probabilmente la parola LIBERTÀ non sa manco cosa (university, south, Pos. 1255)

Se la risposta alla domanda è, che la vita è più importante della libertà allora tutte le leggi liberticide effettuate fino ad ora sono giustificabili e direi quasi giuste, arrivo a comprendere anche perché il green pass, legge palesemente discriminatoria, sia considerata giusta da molti.

Se la risposta alla domanda è la libertà è evidente che tutto ciò che è stato fatto fino ad ora viene considerato un errore a prescindere se una determinata legge sia stata fatta per salvare delle vite umane.

Arriviamo all'ultima risposta, quella almeno per me, più equilibrata, che la vita e la libertà hanno la stessa importanza. In vista di questa risposta è evidente che prendere delle precauzioni, per limitare il contagio ed i morti, è una cosa giusta e doverosa, quindi saranno inevitabili delle limitazioni (tipo distanziamento sociale, mascherine al chiuso, limitare i posti a sedere ecc.), ma a tempo stesso è importante preservare le libertà di tutti i cittadini. (university, center, Pos. 14996 – 15012)

Che razza di schifosissimo incubo vogliamo lasciare noi in eredità ai nostri figli? Un Regime sanitario? Un Regime che brutalizza ogni giorno le menti e i corpi dei suoi cittadini? Basta! Ribellatevi! (generic, Pos. 2127)

stiamo vivendo in una dittatura sanitaria e un autoritarismo politico che vanno comunque contrastati . Mi chiedo un generale a fare da commissario che se ne esce con parole assurde di voler stanare casa per casa i non 'vaccinati ' ? Questa gente se ne deve andare dal governo. Dobbiamo pretendere di andare di nuovo al voto. (university, center, Pos. 5904 – 5906)

Action plan

È una questione politica ovunque. Se capiamo questo sappiamo chi dobbiamo combattere, è non è certo un virus. (university, north, Pos. 20112)

abbiamo potuto appurare l'intensa attività di dossieraggio anche di gruppi telegram. Insomma, adesso che le adesioni crescono, serve un minimo di 'arte della arte della guerra' (anzi della strategia, giusto per non dare il fianco alle accuse di terrorismo) (university, north, Pos. 20233)

niente disquisizioni che vadano oltre il tema da difendere come l'esistenza o meno del virus, la diatriba no-pro vax, il forum Davis, la depopolazione, la sperimentazione di massa, le varianti, i danni ecc. Sono tutti argomenti su cui si è bruciata l'autorevolezza di molti personaggi in vista, dato che rientrano facilmente nelle etichette per così dire 'disinnescanti' (complottista, laurea su Google, no Mask, no vax, no tamp, negazionista). (university, north, Pos. 3607)

Facciamo un flash mob in cui tutti i non vaccinati entrano tutti in contemporanea dove non possono? Magari correndo in modo da essere sudati (così hanno paura di toccarci) magari con in cappello che dice"l'ebreo si ribella" (generic, Pos. 1007)

firmerete davanti agli occhi increduli del vostro datore di lavoro la vostra dichiarazione di lotta non violenta. La vostra dichiarazione di Sciopero Generale ad Oltranza. Punto. Non serve altro. Saremo 100mila, e bloccheremo l'Italia, gli uffici, i servizi, la produzione. Staccheremo la spina a questo Regime infame. (generic, Pos. 2127)

Summary: explaining green pass opposition without involving vaccines

La tesi principale deve continuare ad essere il fatto che si deve essere liberi di rifiutare un'iniezione, qualunque essa sia. Il corpo è mio e decido io. E se vi convincessero che il siero previene per l'x% il contagio (come alcuni provano ad insinuare) tutta la nostra battaglia cadrebbe? Credo proprio di no. (university, north, Pos. 24367)

Other aspects: COVID-19

Inoltre rispondendo alla patetica provocazione vorrei sottolineare: il 99% dei decessi covid sono di ultraottantenni pluripatologici. (university, center, Pos. 2199 – 2202)

il COVID c'é ma non si può fermare il mondo per questo. É una fottuta influenza, specialmente sui giovani. É morta molta più gente di influenza e non se ne é mai parlato (university, north, Pos. 2864)

Ti rendi conto che stai parlando di un virus di cui nessuno in nessuna parte del mondo riesce a dimostrare l'esistenza? (university, north, Pos. 1328)

il virus non é mai stato isolato né purificato. (university, north, Pos. 6509)

IL VIRUS È SOLO UN MEZZO PER IL RAGGIUNGIMENTO DI ALTRI OBBIETTIVI CHE NON CENTRANO NULLA CON LA TUTELA DELLA SALUTE (university, center, Pos. 8092 – 8095)

In più il più importante medico che abbiamo in Italia, dott. Remuzzi con H index 189, ha stilato da tempo un approvato protocollo di cura. Vada sul sito dell'istituto [name] Negri e si informi. C'è da aggiungere anche il dott. Scoglio candidato al Nobel 2018. (university, center, Pos. 14640 – 14643)

il covid si può curare a casa, con dei farmaci. C'è un gruppo di medici volontari che si occupano proprio di questo. Terapie domiciliari covid, è un gruppo fb molto seguito. (university, south, Pos. 1974)

Ascoltate anche dr Citro dr [name] Montanari dott.ssa Bolgan cosa dicono fanno fatto vaccinare le persone con la paura e con il ricatto sui giovani con il green pass. Ci molte reazioni avverse e non lo dicono resistete per il bene vostro. (university, center, Pos. 4198 – 4200)

La mascherina non protegge dai virus. Crea invece colonie di batteri che vi respirate oltre a porcherie che non vi dico per non passare x complottista. Giuste le osservazioni del collega sulla dott.ssa Gatti. Una grande nanopatologa. (university, north, Pos. 742)

Secondo il dott.Delgado non é un virus a provocare la malattia. Questo ve lo spiego quando ci incontriamo (university, north, Pos. 3485)

Other aspects: Preferred measures

Esattamente, bisogna rispettare tutte le regole per impedire il contagio e quindi mascherine e distanziamento (university, south, Pos. 1467)

se vogliamo essere realmente certi che il virus non si diffonda in università, non dovrebbe essere utilizzato il tampone per chiunque entri in università, essendo l'unico strumento ad alta percentuale di riscontro della presenza del virus? (university, north, Pos. 25297)

Vorrei però che venisse garantita la didattica mista, sia in presenza che online, almeno nel primo semestre in modo da non aumentare il rischio di contagi e permettere a tutti di vaccinarsi. Per com'è la situazione a [place], con i trasporti e tutto quanto, è troppo alto il rischio di contagio anche per chi, da vaccinato, possa essere portatore. Non mi sento di prendermi la responsabilità di stare in giro a [place], anche eventualmente da vaccinato, e mettere a repentaglio la vita di altre persone. (university, center, Pos. 2095 – 2102)

Nonostante la fatica per raggiungere l'università, non è Università quella online, fatta di persone, sguardi, dialoghi CONCRETI; sono proprio la fatica e il tempo impiegati per andare all'università che sanciscono il suo valore fondante e formativo. La didattica a distanza non è un mezzo culturale adeguato. (university, north, Pos. 19204)

il tampone diventa uno strumento economicamente limitante per l'individuo, non essendo per nulla garantita agli studenti universitari la gratuità di questo servizio, con conseguente peso economico su chi sceglie di non vaccinarsi. (university, north, Pos. 25298)

Other aspects: Anti-test and anti-mask positions

Io non ho ancora capito...(e' retorico e sarcastico) perche' per il virus piu' contagioso che si diffonde con una sola gocciolina macche' coll'aerosol, per aria...bisogna bucare fino alla barriera encefalica e fino alla ghiandola pineale? Forse perche' altrimenti non assimili l'ossido di grafene & chissa' cos'altro? In veterinaria si usa da tempo vaccinare per via nasale. Ps. Ci sono stati casi di rinoliquorrea ovvero perdita di liquido cerebrospinale, vertigini, emicranie anomali ecc, ovviamente come con il resto tutto viene puntualmente insabbiato e minimizzato (university, north, Pos. 11697-11698)

> *La mascherina non protegge dai virus. Crea invece colonie di batteri che vi respirate oltre a porcherie che non vi dico per non passare x complottista. Giuste le osservazioni del collega sulla dott.ssa Gatti. Una grande nanopatologa. (university, north, Pos. 742)*

Other aspects: Reliance on anecdotal evidence

> *Mio nonno è morto con il covid. Abbiamo seguito ciò che dicevano i medici delle cure a casa per mia nonna. Lei è sopravvissuta. Mio nonno ha voluto seguire la prassi invece. 2 settimane peggioramento. Terapia intensiva e morte. (university, center, Pos. 13863 – 13866)*

> *Ho parlato con una dottoressa di [place]. Sapete cosa fanno per far credere che in terapia intensiva ci sono solo i non vaccinati? Quando arrivano pazienti covid, anche vaccinati con due dosi, hanno l'ordine di spostare i vaccinati in altri reparti e di lasciare i non vaccinati in terapia intensiva. (university, north, Pos. 24524)*

Appendix 3. Patient narratives – a still undervalued resource for healthcare improvement – Interview guide example (Chapter 7)

DIPEx.CH – COVID-19 interview guide

Preamble

In this interview, you are invited to talk about your experiences of COVID-19. You can mention as much as you feel is relevant and important to you.

In the first part of the interview I will ask you to tell me about your experiences. I may also ask you a few follow-up questions to clarify things you have told me or ask for a little more information.

Once you have finished telling me about your experience of COVID-19, I may have a few extra questions about other aspects of your story, such as the 'medical', personal or social dimensions of your experience. If at any point you wish to stop, or if there are questions you don't wish to answer, just let me know.

Part one. Invitation to tell the story of own experience

Please tell me about your experience of COVID-19, from when you first noticed something was not quite right through to when you felt you were fully recovered, including any experiences you have had with health and medical care and any other supports you received. We are interested to understand not only the physical aspects of being ill with COVID-19 but also the emotional or psychological / mental health impacts, and the impact of having the virus on your personal life, relationships and work or other activities you are involved in.

Please feel free to talk about all that is important for you and which you feel comfortable talking about.

* Leave participant to talk as long as she/he/they want or need to.

Part two: follow-up prompts to cover any topics not covered in interviewee's narrative (as appropriate to the individual circumstances)

1. Knowledge about COVID-19

- What is your understanding of COVID-19 and what causes it? How do you think you were infected with the virus?
- Can you tell me what you knew about COVID-19 before you realised this was an issue for you?
- What are your main sources of information on COVID-19? (press, websites, tv, …)
- Throughout your experience of COVID-19, from where did you get information about the virus and what to do if infected? (e.g. health practitioner, clinic, friends / relatives, internet (websites, social media, apps, blogs, online support groups / forums)
- What kind of information were you looking for? (e.g. medical information, people's experiences, information about personal / social aspects of COVID-19, research-based information)
    - Could you find it?
- What kind of stories or rumours have you heard about the origin of COVID-19?
- What kind of information was most / least helpful? Why?
- Do you know someone who had COVID19?

2. First signs and symptoms

- What were the first indications for you that you were unwell?
- Did you think those signs / symptoms may have been due to COVID-19? If not, what did you think they were due to?

3. Diagnosis

- *[If diagnosed]* Could you describe your experience of being diagnosed with COVID-19?
- *[If not diagnosed]* Could you describe your experience of realising that you likely had COVID-19? Did you have contact with (over the phone or in person) a health practitioner about it?
  - *[If no]* Can you tell me a little about why not?
  - *[If yes]* Can you tell me about your experience with the health practitioner and what happened?
- Other topics to ask about re: diagnosis:
  - Any tests / investigations
  - Where the diagnosis occurred (e.g., GP clinic / hospital / specialised COVID-19 assessment clinic ('fever clinic') / other)
  - Receiving the diagnosis:
    - Who made the diagnosis?
    - How was your problem named by a health practitioner?
    - How was the diagnosis delivered?
  - Other underlying / co-existing health conditions and relationship with COVID-19
  - *[If have a partner or family members]* Role / reactions of partner / family members

4. Physical experience of COVID-19

- Please describe your experience of what COVID-19 was like for you physically, from when you first noticed symptoms through to when you recovered. (e.g. What symptoms did you experience, did those symptoms change over time and if so how, which symptoms bothered you most / least, how did you manage them, how did your symptoms interact with any pre-existing health conditions?)
- Symptoms to ask about: dry cough, fever, breathing difficulties, fatigue, loss of sense of smell and taste, any other symptoms

5. Treatment(s) and self-care

Treatment

- Can you tell me about any treatment you had or are currently undertaking for COVID-19.[1] We are interested in both medical treatment (including over-the-counter medicines) and other treatments, e.g. complementary / alternative remedies.
- [If underwent treatment]: Decision-making:
    - Can you tell me about how you came to decide to try those treatments?
    - *[If partnered / have other family members]* What role did your partner / family members have in the decision to try those treatments?
    - What options were presented to you by your health practitioner?
    - Did you do your own research? (Explain that you will ask more about this later.)
    - What kind of support and information did you (and your partner / family member) have in making decisions about treatment? Was it enough / too much?
- Other topics to ask about re: treatment/s:
    - *[If hospitalised]* Experiences of supportive care / respiratory management (e.g. nasal prong, Hudson mask, intubation and mechanical ventilation etc)
    - Effectiveness & side-effects / unwanted effects
    - Emotional / social aspects of treatment (relationships with family, friends etc)
    - Stopping / completing treatment
    - How could information about available treatment/s be improved in your view?
    - have you heard about any complementary or alternative treatments for COVID-19? Did you try any of these?
- *[If did not undergo treatment*] Can you tell me about why you did not have any treatment? What sorts of messages or instructions did you receive from others (e.g. health practitioner / partner / family members) about not having treatment and remaining at home in isolation?

Self-care

- Please tell me about your experiences of self-care (in home isolation). What advice did you receive about in-home isolation from your health practitioner? Did they monitor

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[1] There are currently no pharmacotherapies that have been proven to be effective for COVID-19 - we expect that participants' answers will reflect this and likely focus on self-care or respiratory management if they were hospitalized. However, by asking this question in an open-ended way, we may find out if any participants have been offered any kinds of medicines / therapies.

you in any way (e.g. telehealth consults)? What were the emotional / social impacts, e.g. how did you feel, did you have anyone to help you, and if so, how was your relationship with those people impacted by your in-home isolation?

6. Health care and communication

- Can you tell me about the health services you had contact with, and what for? (e.g. public or private, hospital or outpatient; for testing / diagnosis / treatment)
- Do you think there are significant differences between private and public care? (if relevant, depending on the context)
- Did you receive any follow-up? (e.g. how often, with whom, what tests, feelings about)
- Encounters with health practitioners? (e.g. what specialties? What was helpful / unhelpful?)

7. Emotional / mental health aspects of COVID-19

- Please tell us a little about how experiencing COVID-19 affected you emotionally / psychologically or impacted on your mental health.
- Other topics to ask about:
    - How did you feel when you were first diagnosed?
    - Were you afraid and why?
    - What was it like being in isolation at home / in hospital while you were ill?
    - Were you fearful of possibly dying from COVID-19? Please tell me a little about that.
    - Did you feel anyone treated you differently because you had COVID-19, whether a health care practitioner or someone you know personally? How did that make you feel?
    - What kind of psychological / mental health support would have been helpful to you while experiencing symptoms of COVID 19?
    - Who do you think should provide this support?

8. Impact on personal life and relationships

- How has experiencing COVID-19 impacted on your sense of self, e.g. your identity / self-esteem / life plans?

- Please tell me a bit about the impact experiencing COVID-19 has had on your everyday life, e.g. work / study / other daily activities.
- Impact on relationships (e.g. partner, children, friends, other relatives) & social life in general
- Other topics to ask about:
    - Financial issues (cost of treatment, sick leave, government benefits, health insurance)
    - Social support (what kind, from whom)
    - Feelings about family members trying to help / understand
    - Relationships with others who also experienced COVID-19 *[if any]*
- Did your spirituality/religious views play a role in your experience with COVID-19?

9. Recovery / advice to others / thoughts about the future:

- Please tell me a little about your recovery from COVID-19. (alternative in case of long COVID: Please tell me a little about your ongoing recovery from COVID-19 / ongoing experience with COVID-19)
- What advice would you have based on your experience for:
    - others experiencing COVID-19
    - family members and friends of people experiencing COVID-19
    - health practitioners / health services treating people experiencing COVID-19
    - Is there any advice you would like to share with people who are not protecting themselves and the others from COVID-19?
- People who have been through COVID-19 often notice things about testing, diagnosis, treatment or even government policy that don't seem to make sense or seem inefficient, misleading or confusing.
    - Was there anything of this nature that you noticed?
    - If you could change anything about experience (medical and/or social) of other people experiencing COVID-19, what would it be?
- How do you see your future? (e.g. outlook, impact of COVID-19 on your sense of self, long-term health / mental health impacts, work, study, finances, feeling safe)
- When life returns to 'normal', what aspects of your 'old' life do you look forward to having back? What aspects would you not want back?
- What were the best and the worst things in your experience with covid-19? (alternative: what was the most difficult thing? And what did you learn?)

- If there was one thing you wanted people to know about COVID-19, what would that be?
- Accepting to do this interview you accepted to tell and to share your personal experience. what does this mean to you?
- Is there anything else I haven't asked about that you'd like to mention?

Appendix 4. Patient narratives – a still undervalued resource for healthcare improvement – quality control criteria (Chapter 7)

0. Education and training

- Do you have **experience in qualitative research** (project planning, interviewing, data analysis)?

- Do you know the **DIPEx Methodology**? Are you familiar with the current version of the **HERG Handbook**?

- Have you been **formally trained** before starting a module?

- Do you regularily attend **international DIPEx meetings**?

1. Ethical approval

- Are you using the **standard methodology?** →

Check the KEK approved research plan: Z:\LBE\Forschung\Dipex\Dipex Management\2. Ethics Application\01_Ethics Submission

Cite in your research proposal the appropriate BASEC-Nr: 2017-00678 and 2018-00050

- Are you changing something? →

Develop and submit a CEBES application: https://www.ibme.uzh.ch/en/Biomedical-Ethics/Research/Ethics-Review-CEBES.html

Develop and submit a KEK application: https://swissethics.ch/basec_frontend_faq/knowledgebase.php

2. Interview guide

- Is it grounded on **existing literature?**

- Are **other stakeholders** involved in developing and **revising the first draft** (expert patients, relatives, HCPs, ...)?

- Is it **pilot tested** with a **colleague** experienced in qualitative research?

- Is it pilot tested with an expert patient?

- Is it efficient to **elicit open narratives,** or it is just a list of questions?

- Are there any **linguistical issues** (e.g: use of language-specific, non-translatable words, sentences or constructs)?

3. Data collection

- Are you building your sample keeping in mind **maximum variation** and **theoretical saturation**?

- Do you have instruments to assess **maximum variation** and **theoretical saturation**?

- Are you using the **appropriate consent forms** for the first consent (=to record the interview and to use it for research and teaching)?

- Are you **archiving first consent forms** in an encrypted container, not stored in the same place as the data?

- Are you **avoiding to open audio files with iTunes** or other software creating cloud copies?

- Are you informing your participants of the fact that **transcribed speech looks weird,** and that they don't need to **correct the grammar**?

- Are you taking **field notes after the interviews** (demographics, personal background, medical background, other information relevant for your project)?

- Are you preparing, processing and sending/receiving the data according to the Data Management Guide?

- Is the transcription performed in accordance with the **transcription rules**? Z:\LBE\Forschung\Dipex\Dipex Management\0. Project management\06_Transcription\Transcription rules

- Are you **checking the transcripts** (or having them checked, if in a language you don’t master)?

- Are you using the **appropriate consent forms** for the second consent (= publishing selected extracts of the interview)?

- Are you **archiving second consent forms** in an encrypted container, not stored in the same place as the data?

4. Coding

- Are you **preparing the MaxQDA file** following the procedures explained in the **Data Management Plan**?

- Are you coding using **english codes** on the **original, non translated** interview?

- Are you involving native speakers to code interviews in languages that you don’t speak?

- Did you write an **explanation of your preconceptions** before and during coding?

- Are you building your preliminary coding tree bottom-up, grounding each code in the data?

- Are you challenging your preconceptions, allowing the **emergence of new topics** (‘’sparring between transcripts and interview guide’’)?

- Are you **discussing your preliminary coding tree with peers** (including people speaking different languages and having a different background) in order to consolidate it?

- Are you writing **explicative memos** for your codes?

- Are you writing a **coding diary** while coding?

- Are you using **120-200 codes** (after the consolidation of the coding tree)?

- Did you discuss your coding tree with your **advisory board**?

- Did you check for **intersubjective agreement on the coding** (peer review and communicative validation via collective coding and/or re-coding of selected snippets)?

- Are you coding with a specific code sections that are **potentially interesting for the website** (e.g: ''DIPEx interesting quote'')?

5. Web Deliverables

- Are you involving an **advisory committee** (including **patients**) in the evaluation of the material to be put online?

- Are you involving **patients' organizations** in the **dissemination** of the online module?

- Are your data anonymized and **available for secondary research**?

Appendix 5. Patient narratives – a still undervalued resource for healthcare improvement – participant information sheet (Chapter 7)

Participant Information Sheet

Project Leader

…

Project Team

…

…

…

Dear Sir/Madam,

We warmly invite you to participate in our project "DIPEx" (**D**atabase of **I**ndividual **P**atients' **Ex**periences) and would like to gain your insight as an interview partner.

Goal of DIPEx.ch:

In our project, we would like to explore and understand what people experience with COVID-19. We would like to talk to you about how the disease has changed your life, how it affects your family, your friends and your work, how you deal with it and/or what treatments you have tried.

We would also like to publish the interview in video, audio and/or text excerpts on the "dipex.ch" website, where you will find more stories such as yours. We conduct interviews on various illnesses and other health topics with 40 to 50 people each in selected sections on the website.

The Interview:

The interview can be held at your home, or at a location of your choice, or with an online video-conferencing system and is recorded either in audio only, or in audio and video, depending on your preferences. The interviewer will ask you to tell the story of your condition, and to mention anything that is important to you. Following this, he or she will ask some more in-depth or broadening questions.

The interview takes approximately 2 hours.

We will transcribe the interview and will delete all references to your identity such as names and places. The transcript will then be sent to you, and we ask you to decide upon the following questions:

- whether you agree to publish excerpts of your interview on the Website,
- whether certain excerpts may not be published,
- in which form your interview excerpts are published on the Website (video and/or audio and/or text file),

The Project DIPEx.ch

This project is a long-term study, on whose website DIPEx.ch people who may be going through a similar health experience can find out how other people live with and experience the same disease. It is also available for training and further education purposes. Medical students and health care professions and people who work in the health care system can better comprehend what patient's experience are and what is important to them. The scientific evaluation of the interviews also contributes to improve patient care and supports quality improvement in healthcare.

Our project is part of the international DIPEx network that was founded almost 20 years ago in the United Kingdom. The English website (www.healthtalkonline.org) features over 100 health conditions.

In Switzerland, we are currently in the process of setting up the website www.DIPEx.ch with the help of public research funds and funds from private foundations. DIPEx.ch is a collaboration between the Institute of Biomedical Ethics and History of Medicine (IBME) at the University of Zurich, and the Department of Health at the Zurich University of Applied Sciences (ZHAW) in Winterthur.

Participation:

Participation in our project is completely voluntary. Choosing not to participate will not affect the quality of the medical care that you will receive. You confirm your willingness to participate by a written declaration of consent. If you sign this form, you give copyright of the interview to the University of Zurich, Institute of Biomedical Ethics and History of Medicine (IBME).

The material on the website is protected by copyright and third parties are not allowed to copy or record the material. You can revoke your participation at any time, even after consent has been given, in which case all recordings and transcripts of your interview will be destroyed. We will also remove all contributions from your interview to the website. If you decide to withdraw after your interview has been published on the website, DIPEx.ch cannot guarantee that copies have not been made by third parties. DIPEx.ch has no access to the archives of search engines, which may still provide access to data although it has been removed from the website.

The study is conducted in agreement with the Swiss Law and international guidelines. The ethics committee of the Kanton of Zurich has reviewed the study as not harmful to participants "Nichtzuständigkeitserklärung" (BASEC- Nr. Req-2018-00050). In addition, the "CEBES" (Checklist for the Ethics Review Process of Empirical Studies) Commission of the University of Zurich has approved the project.

Data Protection:

The interview will be done online on video.meeting.uzh.ch, a safe videoconferencing platform set up by the University of Zurich. The servers are located in Zurich, in the University's own data centres. The data stream is end-to-end encrypted, so no one can intercept the conversation. The stream is recorded locally by the interviewer on his computer, then uploaded on the University's server and deleted from the computer of the interviewer. No third parties are involved.

The audio or video file as well as the written interview are provided with a number and stored on computers of the University of Zurich. Your consent form, with your name, will be stored separately from your interview data. The list attributing codes to interview participants will be kept securely, and is accessible only by internal project members. All data related to your interview, including consent forms, are only accessible to staff members. All staff members are obliged to secrecy.

The interviews are transcribed without your name. If you agree to the interview being published as a video or audio file, all references to your person will be muted, so that they are not audible.

On the website, your name will be replaced by a pseudonym, without any personal information such as your name or place of residence, etc. However, if you have agreed to the interview being published as a video or audio file, you will be recognisable through your image or voice. Publication on the Internet implies that third parties can use the data. The recordings and/or still images can thus be used in the press, radio and television. In the case of scientific use, analysis of information from your interview will also be done on anonymized transcripts, with all personal identifiers removed prior to analysis.

Contact:

If you can imagine participating in our project, please contact us so that we can arrange an interview. We would be glad for your support with the DIPEx.ch project. If you have further questions, please feel free to contact us, and we will do our best to answer them for you.

Of course, you can also contact us at any time after the interview if you have any further questions.

Project Leader DIPEx:	Project Team DIPEx:
Prof. Dr. med. Dr. phil. Nikola Biller-Andorno Institute for Biomedical Ethics and History of Medicine (IBME), University of Zürich Winterthurerstrasse 30 8006 Zürich Tel: 044 634 40 80 E-Mail: nikola.biller-andorno@ibme.uzh.ch	Susanne Joebges Institute for Biomedical Ethics and History of Medicine (IBME), University of Zürich Winterthurerstrasse 30 8006 Zürich Tel: 044 634 40 80 E-Mail: susanne.joebges@ibme.uzh.ch

Appendix 6. Patient narratives – a still undervalued resource for healthcare improvement – Informed consent 1 (Chapter 7)

Declaration of Consent to participate in and record an interview for the project DIPEx.ch

Participation in interview for the module "COVID-19"

Name		D.O.B	
Surname			

I have been informed by the attached information sheet about the content, purpose and implementation of "DIPEx.ch" and have received a copy of this declaration of consent.

As described in the information sheet, the first step of my involvement in the study is a video- and/or audio-recorded interview about my health experience.

The interview will happen on video.meeting.uzh.ch, a safe videoconferencing platform set up by the University of Zurich. The servers are located in Zurich, in the University's own data centres. The data stream is end-to-end encrypted. The stream is recorded locally by the interviewer. No third parties are involved.

I understand that the conversation will be written out and all references to my identity (such as my name, etc.) will be changed or removed. The transcript will be returned to me to review, together with a second declaration of consent. I can then decide if I would like the interview to be published on the Internet, and how (i.e. as a video, an audio recording, or text).

I understand,

- that the recordings are voluntary when participating in the study
- that I can withdraw my consent to participate in the study at any time without any disadvantages. In this case, the audio or video data will be deleted immediately.

I agree that the interview will be recorded in *(tick as appropriate)*:

☐ Video and audio
☐ Audio only

I agree to the full use of my interview, and the corresponding data provided by myself as part of the study, for scientific research and training purposes. I understand that details that may identify me will be removed from my transcripts, and that my documents will be saved under an assigned code to protect my privacy. I agree that this anonymized data can be saved in full.

I am aware

- that my consent to the use of my interview for research purposes is voluntary, and
- that I can withdraw my consent at any time.

______________________________ ___________________________

Date, Place Signature

I agree to be contacted for future related research projects. My contact details will remain stored beyond the end of the research project.

☐ Yes
☐ No

Appendix 7. Patient narratives – a still undervalued resource for healthcare improvement – Informed consent 2 (Chapter 7)

Declaration of Consent for the online publication of interviews as part of the project DIPEx.ch

Participation in interview for the module “COVID-19”

Name		D.O.B	
Surname			

I have been informed by the attached information sheet about the content, purpose and implementation of "DIPEx.ch" and have received a copy of this declaration of consent. I was given the opportunity to ask questions.

I have previously consented to the recording of my interview. The transcript of the interview will now be presented to me and I can decide whether and in what form the interview will be published on the Internet - without mentioning my real name. I can indicate whether I agree to a publication of the entire interview, or whether I do not release certain interview excerpts for publication.

I have read the transcript of my interview, and agree to publish it on the Internet as a/an:

(please only tick ONE option)

☐ Video recording with accompanying written text
☐ Audio recording with accompanying written text
☐ Written text of my interview only
☐ None of the above

I consent to excerpts of my interview being published on the Internet based on:

(please tick only ONE option)

☐ The entire interview

☐ Only the portion of the interview as chosen by me (I have marked the passages that are NOT to be published)
☐ Not applicable (i.e. I do NOT consent to publishing my interview online)

________________________________ ____________________________

Date, Place Signature

I am aware that:

- publication of my interview on the Internet is voluntary, and
- I can withdraw my consent to the publication of my interview on the Internet at any time. My interview material will then be immediately removed from the website „DIPEx.ch", in which „DIPEx.ch" has no influence on any copies made before that point, and
- I assign my copyrights for the interview to "DIPEx.ch". Therefore, Copyright will lie with the Institute of Biomedical Ethics and History of Medicine (IBME) of the University of Zurich

________________________________ ____________________________

Date, Place Signature

13. Curriculum Vitae

Giovanni Spitale

Date of birth: December 3rd 1987 | Nationality: Italian

EDUCATION

Period	Title	Topic	Institution
2018 – 2022	PhD	Biomedical ethics	University of Zurich, Institute of Biomedical Ethics and History of Medicine
2012 – 2015	MA	Philosophical sciences	University of Padova
2006 – 2011	BA	Philosophy	University of Padova
2001 - 2006	Maturità Scientifica		Liceo Jacopo da Ponte, Bassano del Grappa

EMPLOYMENT

Period	Position	Role	Institution
2018 – ongoing	Research Assistant	Research data management	University of Zurich, Institute of Biomedical Ethics and History of Medicine
2017 – ongoing	Copy strategist	Editorial services and copywriting	Storyteller-labs
2015 – 2017	Teacher and educator	History and Philosophy teacher in high school	Istituti Paritari Filippin
2014 – 2015	Copywriter	Editorial services and copywriting	Officine Micrò
2012 – 2013	Communication manager	Management of the communication department, outdoor and mountaineering	Montura