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OPEN LETTER

REVISED **Cancer, COVID-19, and the need for critique [version 2; peer review: 2 approved]**

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Abstract

In this open letter we examine the implications of the coronavirus disease 2019 (COVID-19) pandemic for cancer research and care from the point of view of the social studies of science, technology, and medicine. We discuss how the pandemic has disrupted several aspects of cancer care, underscoring the fragmentation of institutional arrangements, the malleable priorities in cancer research, and the changing promises of therapeutic innovation. We argue for the critical relevance of qualitative social sciences in cancer research during the pandemic despite the difficulties of immersive kinds of fieldwork. Social science research can help understand the ongoing, situated and lived impact of the pandemic, as well as fully underline its socially stratified consequences. We outline the risk that limiting and prioritising research activities according to their immediate clinical outcomes might have in the relational and longitudinal understanding of cancer practices in the UK. Finally, we alert against potential distortions that a "covidization" of cancer research might entail, arguing for the need to maintain a critical point of view on the pandemic.

Keywords

Cancer, COVID-19, Social Sciences, United Kingdom



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report



report

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Any reports and responses or comments on the article can be found at the end of the article.

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REVISED Amendments from Version 1

We have revised the open letter following the comments of the reviewers. We have described more in depth the contributions of ethnographic methods to the study of illness and medicine, both in general and specifically in the context of the Covid-19 pandemic. We have further clarified the concept of “covidization”, which we use to describe the problematic tendency to attribute all the problems of healthcare systems emerged during the pandemic to the pandemic itself, ignoring how many problems were pre-existing. We further describe the public/private mix in the British NHS, and we have introduced some minor revisions to reflect the changes in the pandemic since the initial version of the open letter.

Any further responses from the reviewers can be found at the end of the article

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The entanglements between cancer care and COVID-19: A multi-layered disruption

The coronavirus disease 2019 (COVID-19) pandemic has abruptly altered the lives of millions and caused major disruptions to those classified as the most vulnerable segments of the population by the UK Government, including patients living with cancer. Millions of elective operations have been postponed ([Sample, 2020](#)), with pathways altered (see [Cancer Research UK news article](#)), waiting times increased, screening programs suspended ([Maringe et al., 2020](#)). Medical personnel have also been placed under significant and sustained stress (see [BMA mental health wellbeing report](#)). There has also been a significant upheaval in the ordinary activities of NHS trusts, professional bodies and structures already enduring austerity and managerialisation policies. Such upheaval had marked consequences for cancer care. Since the start of the pandemic in the UK, several articles have brought forward the testimonies of patients whose treatments have been interrupted or delayed or who were alerted that they would have not found a place in ICU had they contracted COVID-19 ([Hughes, 2020](#)).

Modelling approaches to statistically estimate the disruption brought by the pandemic are focusing mainly on excess mortality and life-years lost, something that it is in itself difficult to ascertain within the current time-frame. [Sud et al. \(2020\)](#), focusing on mortality derived from diagnostic delays, alert that “[u]nlike acute pathologies, such as stroke and myocardial infarction, the true excess mortality due to COVID-19-related disruption to cancer pathways will not be fully evident for 10 years or longer”. These distal statistical approaches make it difficult to garner a full understanding of how and for whom cancer services have been disrupted, particularly because such modelling work claims that we will only be able to understand the disruption after the pandemic, when mortality data becomes available and clarified. This risks occluding the real-time, on the ground, disruptions to cancer services. We therefore require

different empirical and theoretical approaches to document and understand these developments.

Longitudinal observational work within the social sciences is primed and critical to illuminating the multiple tensions that are informing clinical dynamics. Ethnographic work, in particular, privileges in-depth accounts of the “on the ground realities” experienced by multiple stakeholders. It offers unique insights into different timescales, experiences, and points of view, and further how these are related and held in tension. Yet, such work in cancer contexts has also been interrupted during the pandemic, due to a number of conditions and for a variety of reasons. Patients, relatives and healthcare professionals who experience proximal disruption are required to deal with novel situations and improvise care-work practices within changing terrains. Yet, disruptions are emerging across the cancer care continuum and are not limited to pausing screening and diagnostic delays, but also involve patients already in treatment and those in follow-up care. Those who are affected by advanced cancer often rely on clinical trials to access potentially life-lengthening treatments. Because of their bodily vulnerability, this segment of patients is particularly impacted by the suspension of research on cancer and of clinical trials. However, we must keep in mind that some of the features that are considered to be disruptions for the patients might not be perceived as such by the medical professionals, and vice-versa. The difficulty of in-person consultations, in some cases substituted by telephone and/or online exchanges, as well as not being able to have an accompanying person (e.g. friend/relative) attend appointments, have a different impact for patients than for clinical professionals – these are consequences that are often difficult to anticipate. Understanding the different ways in which cancer care has been impacted by the pandemic therefore requires to look at an ample range of alterations, both immediate and long-term, to cancer care. Such an understanding – a project for which the social sciences are pivotal – is greatly needed in order to plan supporting mechanisms for the patients and the full reactivation of services.

This open letter is the result of an online workshop organised in late September 2020 on the mutual implications between cancer care and COVID-19, involving six researchers whose scholarship concerns the practices, experiences and ideologies informing the fields of cancer in the UK. The workshop was motivated by the need to make sense of the barriers we must navigate while carrying out cancer ethnographies in the UK. It extended from there to reflect on the impact of COVID-19 on cancer care, including some aspects of cancer care that remain uncertain because of the lack of ethnographic or other kinds of data.

The fragmentation of cancer care

In addition to the disruption to NHS services, charities working both on cancer care and cancer research have experienced significant difficulties since the beginning of the pandemic, with income yielded from donations dropping suddenly and ensuing restructurations of their own operations (see [Cancer Research UK blog on funding cuts](#)). While the UK has been characterised historically by the prominent role of the state in funding and

providing healthcare, with a somewhat limited role for “for-profit” or private social actors, since the 1980s there has been an increase in the private healthcare sector and its partnerships with formerly public research and clinical institutions. These partnerships become visible through particular mechanisms, such as in the increasing outsourcing of NHS services to private firms, the growth of private research enterprises partnering with NHS bodies to harness rich and centralised data and to invest in translational research, and the role of private charities in enabling research and delivery of cancer therapies. Medical charities in the UK not only fund basic and population-based cancer research, but they also offer guidance and support to patients with cancer both outside and inside the NHS, also delivering pan-cancer rehabilitation services across the country (e.g. Macmillan Cancer Support among others). The ongoing crisis that cancer charities are facing reveals a significant paradox. Most charitable organisations have developed either to cover areas that had limited public support (e.g. Marie Curie provides community palliative care) or to cover areas from which the public services have retreated, with hindsight, such as the case of psycho-social support.

Due to the pandemic, even a government guided by a political party historically hostile to public spending has taken some exceptional policies to alleviate bottlenecks and improve access to treatments in a healthcare service overwhelmed by demand. This has shown the possibility, and arguably the necessity, for centralising healthcare services and resources under public control to deal both with peaks in the number of cases, and the continued provision of ordinary healthcare needs. However, a significant part of the care that patients rely on is managed through charities, which because of their financing model, legal status, and organisational structure, are difficult to centralise under public control. The risk is that even if the government decides to allocate the resources necessary to avoid major disruptions to cancer services during a public health crisis, an important part of the current offer of cancer care in the UK might be significantly affected.

COVID-19 is revealing the fragmentation in cancer care that is located at the intersection between private and public management, charity and industry, also evidencing the persistent effect of austerity policies in the healthcare and social care domains. In this fragmented landscape, some patients find comfort and support in less institutionalised contexts, such as neighbourhood, friendship or cancer support groups. However, the requirement for social distancing during the pandemic has also altered the availability of these forms of help, thus worsening the quality of life of cancer patients who have needed to shield to minimize the risk of contracting the virus suffering from already compromised immune-defence mechanisms.

In this context, it is urgent that we study the real-time changes materialising prospectively so we can both shed light on their implications for all those affected (see [Vindrola Padros et al., 2020](#)) as well as develop rich and sustained scholarship throughout the pandemic. Such analysis better shows how forces and structures which might appear intractable were not

always inevitable, as much long-term ethnographic work attests ([Biehl & Locke, 2017](#)).

(Re)shaping research practices during COVID-19: Challenges and possibilities

Social studies of science, technology and medicine continue to play a vital role in understanding interactions between biology, subjects, and environments. Eschewing simple and reductive accounts, they have tackled social worlds in their complexity and considered the mutual constitution of these domains and entities. Recent scholarship has explored how novel understandings of biology reshape our worlds, organise our societies, and inform how we understand ourselves ([Wahlberg, 2018](#)). Other contributions have mapped the social effects of biomedicine, informing changing perceptions of the body, normative definitions of what is considered to be a desirable behaviour, and public entitlements to health and care ([Lock & Nguyen, 2011](#); [Petryna, 2002](#)). Moreover, many social science scholars have delved into the lived experiences of those seeking care, unpacking the particular relationships through which people affected by conditions withstand disease-related suffering and sometimes find relief ([Das, 2015](#)). This scholarship has also developed critical lenses on emergence, provisionality, revolutionary change and stabilisation in science, technology and care ([Keating & Cambrosio, 2003](#)). In the field of oncology, social science disciplines have played and continue to have important roles in understanding relations among experts and publics, perceptions of risk, experiences of the cancerous body, inequalities in access to standard and experimental treatments, professional practices, informal care work, and the involvement of diverse publics in cancer-related research ([Arteaga, 2019](#); [Arteaga Pérez, 2020](#); [Day et al., 2016](#); [Greco, 2016](#); [Greco, 2019](#); [Kerr & Cunningham-Burley, 2015](#); [Kerr et al., 2018](#); [Llewellyn et al., 2018](#); [Llewellyn & Higgs, 2020](#); [Swallow et al., 2020](#); [Therond et al., 2020](#)). Through an array of ethnographic research practices including interviews, observation, participatory techniques, and archival research, social sciences scholarship has contributed to our understandings of the promises, ambivalences, complexities and difficulties within the biomedical field from the perspective of different stakeholders, including patients, caregivers, medical professionals, scientists, and interested publics.

Ethnographic methods can make an important contribution to how the COVID-19 pandemic has been understood and managed. First, it can understand arising and unfolding issues. To mention two examples, the lived realities of those affected by COVID-19 will be lifelong. Enduring social and health inequalities has made COVID-19 different for different people, as the [Covid Realities](#) project has shown. Moreover, the response of the UK government has been criticised for its temporary over-reliance on behavioural experts and its support of individualised preventive measures. These approaches, we argue, have ignored equally significant collective measures and responses that involve the re-organisation of working life and the economy. By describing “people in context” ethnographic approaches can combine state-sanctioned individual responses with collective and other perspectives whose conception of personhood is not

reducible to pre-given national, ethnical, biomedical, or other categories. Second, ethnographic work is crucial to give a more situated and therefore relational understanding of the experiences and mechanisms through which care is negotiated and embodied. An essential part of what matters to people cannot be captured by quantitative metrics. Or by numbering practices underpinned by methodological individualism. Ethnographic analysis can provide rapid and systematic estimation of social challenges that affect communities' resilience and their capacity to withstand the effects of the pandemic. Reports such as [A Right To Care](#), for example, offer important insight into how we can make recovery plans and policies workable and inclusive.

Over recent months each of us - as social scientists, members of families, and civic actors - have found ourselves dislocated from our assumptions and routines pre-COVID-19. This visceral sense of dislocation contributes significant social and professional challenges. However, it also provides a new critical space to reflect, amongst other things, on how we are able to conduct and communicate our research in this time of COVID-19.

As large portions of our social life have been redirected online, the social sciences are also in the process of adapting methods and theoretical frameworks to better understand the challenges posed by the pandemic to those affected by cancer either personally or professionally. The discussion emerging from the workshop demonstrated how, as social scientists, our current research practices have not only been constrained by the pandemic but also reshaped. As ethnographers, we are all too aware that barriers to the "on-the-ground," in person, physically-situated component of our work - momentarily or for longer periods - poses risks to research practice. Online and remote research, while offering safer access to the communities with whom we work, cannot fully grasp the material and contextual nuances that inform people's everyday efforts; it changes the relational dynamics between the ethnographer and participant, and the opportunities for participant-observation in field sites as a core ethnographic endeavour.

Part of the difficulties we are experiencing in relation to the current constraints of immersive and situated research methods in social research parallel those of medical professionals and patients, whose own relations have also been redrawn. For medical professionals, virtual approaches bring challenges to usual techniques of assessing, supporting, responding to and caring for patients. For patients, daily routines have been radically disrupted, care provision has been redefined with cancelled appointments and procedures, and virtual follow-up clinics. All are subject to increased uncertainties in their lives and work, coupled with on-going emotional labour that characterises provisional and highly precarious knowledge, policy and practice about the pandemic.

Moreover, online recruitment strategies in social science research can privilege participants who tend to have more resources and time at their disposal, inevitably skewing the range of

lived realities we are able to encounter as researchers, given that internet access reflects wider social and structural inequalities. As with social scientists, clinical research coordinators must grapple with the sample bias that the COVID-19 pandemic might pose, considering their own mandates to protect patients from the intrusion of research into clinical pathways, which might stand for an essential component of care. Whilst clinical experiences and practices are changing, our methodologies start reflecting and recording those changes.

This pandemic, while sudden and harsh, is not the cause of all the current problems in healthcare settings, but a contributor, catalyst and powerful amplifier. The pandemic has exacerbated existing fragilities and reactivated old fault-lines that research on healthcare services and oncology has already shown ([Arteaga et al., 2019](#)). With this in mind, we think it is important to resist the temptation to divide the reality in a pre- and post-COVID-19 and instead look to critically reflect on the role of social science and qualitative research specifically for addressing these challenges whilst also reflecting on the emergence of alternative knowledge-making practices.

The covidization of research: the role of qualitative social science research

Aware of the continuity between the clinical, financial and political difficulties already existing in the National Health Service before March 2020, we are cautious to not fall into the "covidization" of all scientific research ([Pai, 2020](#)). By "covidization" we refer to the tendency of approaching the study of the COVID-19 pandemic, by attributing all the problems that have emerged to the pandemic itself. We argue that rationing available resources and directing them to this research agenda risks overlooking other enduring problems within the organisation of healthcare and medicine. With restrictions to social life still in place, the pandemic seems to be, if not the only, certainly the dominant interpretative framework to analyse the present, especially in the biomedical field. Embedded at various levels, from funding, research portfolio management, research ethics, study sponsorship, capacity and capability assessments; and through the discretionary decisions of clinical teams, this framework has had significant impacts on the development of research infrastructures and consequently the kinds of knowledge that are produced. A recent consensus-building paper produced by Cancer Core Europe ([van de Haar et al., 2020](#)) suggests to "reduce preclinical research activities to a bare minimum" and "stop patient inclusion for clinical studies or trials requiring additional actions and/or visits" (667) - this, in practice, makes translational cancer research an exception. Moreover, in a demonstration of "ethical variability" in clinical care ([Petryna, 2005](#)), the authors argue for the need for the selective "adjustment" (that is, de-escalation) of anticancer therapeutic regimes during the pandemic. This involves the hypothesis that the de-escalated treatments could be normalised post-pandemic if the clinical outcomes are not inferior to those of the pre-pandemic treatments. As a prime example of the covidization of research, the published roadmap claims that "[t]he COVID-19 pandemic may offer a unique window of opportunity for retrospective trials, assessing the non-inferiority

of de-escalated treatment regimens, which may be difficult to perform under normal conditions for ethical reasons” (670).

The redefinition of research activities during the pandemic intersects with and reinforces pre-existing professional, institutional, disciplinary and epistemological hierarchies. Whether pre-approved studies are funded by the National Institute of Health Research (NIHR; the largest funder of health and care research in the UK) or not, frameworks such as the NIHR Restart determine what is considered “urgent” and hence of essential value (defined as “patient benefit” and health delivery “cost-efficacy”). NIHR Restart then sifts through particular studies in relation to present and potential risks, prioritising certain (clinical, measurable) approaches while stalling others (social, critical) where value is difficult to estimate.

Although such logics of urgency and priority are inevitable and important in contexts of radically compromised capacity, we are keen to advocate for guiding principles that accommodate the kinds of critical social science work outlined above, which examines and bears witness to the social consequences of disease and care, and the ongoing articulation of ethical frameworks across a variegated society. In particular, we have in mind approaches that offer ethnographic approaches and those that reside beyond the limits of the clinic, which nevertheless offer an essential contribution to the understanding of the social impact and personal stakes that the pandemic has brought onto healthcare services and people’s everyday lives. If COVID-19 has surfaced the UK’s enduring health inequalities into public awareness, then the organisational streamlining and prioritisation of clinical and biomedical research within the NHS risks, paradoxically, sidelining the social scientific research that can bear witness to the wider social dynamics that are core to COVID-19’s uneven effects. At stake in this “covidization” of research is thus both a broader and more nuanced understanding of the pandemic and its effects and the displacement of important work in other arenas that are not explicitly deemed “COVID-related” (Pai, 2020). Indeed, just as the pandemic exposes and is exacerbated by socio-cultural, economic and political disparities, it is critical that ethnographers are enabled to participate in the disentanglement of the on-the-ground effects of COVID-19 on cancer treatment and care practices across and beyond the UK.

Looking at the future: Intersections between COVID-19 and the promise and practice of personalised cancer medicine

Important innovations in cancer treatments have been linked to the identification of specific biological markers, allowing for targeted therapies for specific subgroups of patients. It is these kind of stratification practices that are behind the promises of what is commonly called “personalised” medicine. The COVID-19 pandemic, and the subsequent success and rollout of the UK vaccination programme, has, in many ways, brought into sharp relief the “circulation of scientific promises” attached to the development and delivery of personalised medicine in oncology and rare diseases (Sturdy, 2017:31).

Yet, we know that the impact of COVID-19 on cancer research communities is profound, as funding and public/private investment is squeezed, and human and non-human resources are re-routed to help tackle the virus’s effect on society and citizens (see [Cancer Research UK Open Letter to researchers](#)). We have seen how laboratory closures, as a result of the national lockdown, slowed down scientific progress thus exacerbating any mismatch between upstream promises in cancer research and their downstream translation into clinical care (see [Cancer Research UK researchers lockdown experience survey](#)). As *Genome UK: The Future of Healthcare* (Department of Health and Social Care, 2020:19) outlined, some of the most exciting developments in early detection involve interval observational studies that track circulating tumour DNA (ctDNA). However, sample collection for such studies are not priorities and involve patients in follow-up; their hospital appointments have been cancelled in recent months. Moreover, even before the COVID-19 pandemic access to clinical trials could be patchy and lacking in patient diversity in places across and beyond the UK (Kerr & Cunningham-Burley, 2015). During the initial months of the pandemic clinical trial recruitment ground to a halt in the UK which meant for many patients a missed window of opportunity to access potentially life-extending drugs.

The current challenge of conducting social science research in the clinical settings means examining the broader social impact of the pandemic on the practices of personalisation are yet to fully materialise, teasing out how the pandemic intensifies micro and macro-level asymmetries of personalised cancer care is particularly important. As patients navigate an even more uncertain landscape of complex care, the pandemic reminds us of the ongoing, and in fact urgent need to scrutinize the meaning of personalisation. Indeed, the virus continues to demonstrate how a truly personalised approach in healthcare should not be confined to the biological aspects of treatments but must also consider the needs of the patient from a holistic point of view (Day *et al.*, 2016; Kerr *et al.*, 2021; Prainsack, 2018).

A third “C”: The need for critique

While seeking to acknowledge the impact of the pandemic on research and care infrastructures around cancer, we invite caution towards totalising tendencies. The risk of covidizing cancer resembles the #ForgottenC, an online hashtag becoming popular in online platforms among charities and other advocacy groups. Remembering cancer during the pandemic presumes to know and thus recall cancer as a figure being forgotten. We want to call attention to work carried out in clinical and non-clinical contexts that highlights the diverse and unequal resources afforded to people using health services in the UK. We encourage our colleagues to look at cancer as a biosocial phenomenon rather than limiting it to the simplified narrative portrayed as part of charitable fundraising efforts.

Reckoning with a #ForgottenC is to do critical work with longer histories of managerialism, streamlining and efficiency saving in the context of public sector austerity, privatisation, biotech and pharma profiteering, and the degradation of hospital

estates. How we remember one C should put to work another: “critique”. Critical work involves considerations of our own privileges, biases and limitations, especially our dependencies on the private wealth of charitable organisations, conditions what social science can do within a pandemic. It involves, again, reckoning with our dependencies, antagonisms, and entanglements with biomedicine. Building on our expertise as social

science scholars in the field of cancer, we sought to outline what a critical, reflexive and provisional approach to Cancer and COVID-19 may involve.

Data availability

Underlying data

No data are associated with this article.

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Christine Schmid 

Department of Psychology and Ergonomics, Technical University of Berlin, Berlin, Germany

I enjoyed reading the open letter "Cancer, Covid-19, and the need for critique". It is a very well-written piece contributing to discussions about the entanglements between Covid-19, cancer care and social science research. The open letter addresses the impact of the pandemic on cancer care, on patient's lives and points out that this current "moment of crisis" reveals a fragmentation in cancer care that already existed before.

However, the main argument, as I understand it, is a call for the importance of - underestimated and neglected within the field cancer research in times of the pandemic - qualitative social science research.

Overall, I think this argument, and in particular its development from the concrete example of the fragmentation of cancer care to the need for critical social scientific debate, works.

However, it might also be this structure that leaves me as a reader missing clarity as to what the authors' main intention or main argument is.

For instance, the description of fragmentation could be elaborated on in more detail, if this is an example for why and how social scientist can contribute to critical research on cancer care. Otherwise, in the end, it is still unclear how this exactly becomes relevant or critical in practice. At the same time, I was wondering, if this reasoning for social sciences as a primarily critical form of knowledge production - without elaborating on its contributions in more detail - reinforces an image of a distanced "critique from outside". Following Latour (2014) this form of deconstructive critique from social sciences is not effective anymore in order to contribute to current social questions. But this might be a follow-up question and not so vital to the letter.

By the same token, I was wondering why the authors did not refer to some more of their own work in order to clarify abovementioned fragmentation - this would additionally support the argument that research should not be divided into pre- and post- COVID-19 research. Also, the examples in the open letter are based on a specific national cancer care context. For me,

as a non-UK researcher, it would help to know more about the division into public and private health care to understand the argument.

On the other hand, I feel that the part on research practices during COVID-19 beyond the description of the current difficulties is too general and only loosely tied to the other parts. I think it could gain if it would be tied to either concrete options and examples of how the authors currently work, or to the question of fragmentation (e.g. along the lines of: does the use of digital counselling in cancer care versus personal counselling lead to another variant of fragmentation?).

Furthermore, I would like to know more about the context of the workshop that led to this open letter. Why did you meet up and organize a workshop? What was your initial question? And how did you end up with this open letter?

All these comments can be addressed relatively easy and I hope that they help to strengthen and clarify the important argument in this text.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Medical Anthropology, Social Anthropology of Science and Technology, Anthropology of Experience, Hospital Ethnography.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 03 Jun 2021

Cinzia Greco, University of Manchester, Manchester, UK

We want to thank Caitjan Gainty and Christine Schmidt for the positive evaluation of our open letter and their constructive comments. We have revised the open letter in several

passages to address some of their interventions – notably, on issues related to the contribution of qualitative social science, the meanings of “covidization”, and the organisation of healthcare in the UK. At the same time, we aimed to keep the open letter relatively brief, reflecting on some of the comments in more detail below.

We have added a few details in the letter itself explaining the context and purpose of our workshop. Having met each other in previous academic meetings, we saw the workshop as an opportunity to discuss, informally, how new difficulties hindered our fieldwork research in the UK in the context of the pandemic. Rather than guiding our reflections with the aid of a set of specific questions, the analysis we presented in the open letter emerged from loosely structured exchanges that took place throughout the process. Cinzia Greco and Ignacia Arteaga collated the reflections presented by participants and started further conversations with all the authors around the text that became the current open letter. The issues we decided to touch upon, expressly limited, aimed to represent some of the domains we were exploring at the moment of writing.

Many thanks to Caitjan Gainty for the remarks about cancer not being exclusively defined as a clinical reality. The same conceptual standpoint is seminal in our work. We agree that cancer is no different from other conditions, even though its high prevalence and public imagery continually shape healthcare dynamics and patients’ relationships. Consequently, we agree that the issues we describe are not limited to cancer. Our choice to focus on cancer is linked to the fact that we have specific expertise as a group of researchers and because specific concerns have been raised regarding the on-going disruption to oncology services caused by Covid-19 within clinical, patient and charity communities (e.g. CRUK). We believe that a more extensive discussion of the impact of the pandemic on healthcare, in general, would need different data-gathering and analysis techniques and a format different from an open letter.

In response to both reviewers’ remarks about our disciplinary contribution to understanding the pandemic and attending to some of its consequences, we have also included a paragraph outlining some of the ways in which social science contributes to the understanding of the pandemic. On the one hand, we can conceptualise the pandemic as a “social fact” that must be understood and unpacked in its differential effects in various domains. On the other hand, the pandemic is also conceived as a reality to be intervened upon to aid the design of recovery plans informed by the relevant issues in people’s social worlds. Importantly, changing the vantage point includes examining and verbalising the normative assumptions that inform policy decisions which is in itself a mode of political intervention.

We have now revised the passage describing the critique around the “covidization” of research, following and expanding on Pai’s argument. We underline that our use of the concept refers specifically to problematic aspects of the interpretation of the pandemic as a cultural form. These include issues in the larger organisation of scientific research. These epistemological issues have to do with the reproduction of long-standing hierarchies of evidence and negative ways in which the COVID pandemic might transform medical practices in a post-pandemic context by diverting resources and attention from long-standing issues that also merit scholarly attention.

Our worries, shared with Pai, are that part of the exceptional effort in terms of research, dissemination, and funding directed at the study of COVID has the potential to overlook previous social and medical issues. In this line, COVID exacerbates and highlights questions for us, rather than creating them ex-novo. We see the problem as partly due to a lack of balance in the research produced. More than this, it is the risk of doing research that disconnects the impact of the pandemic from longstanding issues in healthcare.

We are also concerned that this strategic move might produce a limited understanding of the pandemic by ignoring pre-existing problems that were exacerbated rather than produced by the pandemic. We are among the many who hope the pandemic should be an opportunity to correct part of what was wrong in healthcare. Yet, we see the danger that the post-pandemic might also result in the roll-back of treatments and services that, although convenient for the financial budget of healthcare trusts, is detrimental to patients. Managers' realisation that their hospital trusts and general practices can make efficiencies after the pandemic risks healthcare becoming even more unequal and fragmented.

In a context where some community groups have already troubled stories in their interaction with healthcare, we risk further alienating and excluding those who do not have the resources to become "activated" in their communities, cannot "connect" via virtual technologies, or cannot afford new forms of "patient work" that are now required. Here, "covidization" does not refer to the main topic we are discussing in the letter. Instead, it refers to a specific problem to avoid: addressing COVID by ignoring its links with pre-existing situations and exclusions in healthcare, thereby aggravating them.

For the readers unfamiliar with the British context, we have added a brief passage on the NHS's relation to the public, the market, and the state. The NHS has historically stood out in contrast to the role of the private social and private for-profit actors elsewhere in Europe and, more so, in North America. However, it has seen a steady increase of private actors since the 1980s. While the UK is still a nation with a prominent role given to the state in terms of healthcare funding, we see the continuous outsourcing of several in-house services to private companies, including for-profit entities. More relevant for our analysis, private non-profit charities in the UK have an essential role in funding translational and population research, additional clinical services, and professional positions, such as nursing and palliative care.

We thank the reviewers for their questions and suggestions again. We hope that this response illuminates some of the issues that – no doubt – we need to continue reflecting upon.

Yours,

Cinzia Greco, Ignacia Arteaga, Clara Fabian-Therond, Henry Llewellyn, Julia Swallow and William Viney.

Competing Interests: No competing interests were disclosed.

Reviewer Report 15 December 2020

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Caitjan Gainty 

Department of History, King's College London, London, UK

This open letter is rich and thoughtful. It offers, for one thing, a review of the ways in which the cancer care industry and its actors all along the line - including its frontline physicians and patients - have been impacted by the COVID-19 pandemic. Here, the letter points to accounts of patients whose treatments have been disrupted and whose status within healthcare has changed: from those heavily dependent on the system to those too ill to be treated should they contract severe COVID.

At the same time, the letter points out the dangerous potential for attribution errors during a pandemic, noting that the so-called "covidization" of cancer cuts two ways: in its implication that COVID-19 has actively disrupted cancer research and therapy, it notes the novelty of a once-in-a-generation health event on all aspects of the "regular" system of the cancer care industry. But it also introduces the risk that too much attention to this specialness will paper over what are actually longer-standing continuities, forces or factors attributable to causes outside of COVID-19.

But both of these themes are subordinate to what I take to be the letter's main argument: that those who study cancer from the perspective of the social studies of science, technology and medicine ought to be considered critical players in this discussion - as critical, in fact, as any of the other knowledge-making actors in cancer care - because the factors that they are uniquely equipped to deal with, the biosocial, cultural, economic, political, etc, are just as fundamental to the creation of cancer as any other. In this, the authors are calling for recognition that disease is not just a clinical creation and that as a result the factors relevant to understanding, signifying and managing a disease cannot be limited only to those who experience it clinically.

The authors underscore this point in a variety of useful ways, and I think the argument works by and large, though it remains a question to me whether this is something that the authors feel is specific only to cancer or whether their discussion here is actually more radical, that when we acknowledge, as we publicly do, that medicine and health are more than just clinical entities, it makes little sense to prioritise clinical entities as those suited to define its significance.

Given how potentially important the authors indicate the role of the social scientist is, it feels a bit of a let down that they do not indicate more precisely what it is that the presence of social scientists in cancer's inner knowledge-making circle might yield. The language they use to describe their role is remarkable for its passivity. Researchers "bear witness to" or are "enable[ed]" to "document and better understand". This leaves a hole at the veritable center of the argument: what is it, besides watching and documenting, that social scientists are able to contribute? The translation from arguing the case from a matter of academic necessity to arguing it as a matter of

real-time, real world necessity is not fully described here, even though the real world significance of the authors' work cries out for acknowledgment. What would change if social scientists were in the mix?

I wonder if perhaps this omission is a translational one: the difficulty of describing one's significance in terms other than those internal to one's own work is well known. And if so, I wonder whether the letter is not otherwise troubled by this translation, or perhaps by the artefactual remains of what were clearly wide-ranging and dynamic conversations had at the conference in September. Among other things, the discussion of the difficulties of social scientific research in a pandemic feels very specific, yet the letter is not necessarily otherwise specifically about the difficulties particularly attendant with social science research in a pandemic exactly. The situation is similar with the discussion of the NIHR: a very specific reference that feels out of keeping with some of the more thematic points made in the letter, even if it used to make a point about research priorities. And the discussion of personalized medicine, while interesting and thoughtful, also seems awkwardly bent toward the matter at hand. The reference to Steve Sturdy's work here, indeed, feels a bit of a red herring: I read that work as a rich provocation about how to (re)signify personalized medicine. But this section doesn't follow through on Sturdy's notions of bioetch's "promissory economy" and instead almost seems to double down on a slightly more facile notion of personalized medicine that, given the theoretical richness of their account in other places, seems just out of place.

Both of the above can be addressed relatively easily and are not so vital to the letter's main argument. What should be addressed, I think, is the uncertainty attached to the notion of covidization. Initially, covidization seems primed to refer in quite a facile way to research costs. The referenced text focuses on researchers attracted to study COVID whose loss aggrieves the community of researchers they've left; whose help, for lack of expertise, is actually not helpful to those they've joined; and who thus add to a cacophony of scientific voices rather than becoming a part of a single cohesive sensibility about how to think about and what to do about COVID. This rather reductive view (of covidization but also of scientific research, for that matter) feels out of place, and the examples the authors include of the covidization of cancer don't clarify how their meaning of the term relates to this one.

It seems to me that covidization for the authors ultimately seems to signify something to do with an inability to strike a balance between the novelty of the pandemic, at least in our lifetimes, and its non-novelty, both as a historical phenomenon and as a prism onto healthcare in real time. Does COVID represent a change in kind or a change in degree?

If this reading is right, then we are left with some uncertainty about the status of the letter. Is it suggesting something about the attendant and specific difficulties of cancer and COVID, of cancer as a covidized disease, and therefore the need for social scientific contributions? If so, does this contradict the richness of the definition of covidization that the authors provide? Or are the authors saying that now, as at all times, social scientists need to be involved in the study of cancer? And if so, does this mean that their intonation of COVID here is too strong? Some resolution to this conceptual difficulty would be in order. If, for example, it is that COVID has exacerbated and/or laid bare for us what is already true about cancer, then this is certainly worth saying. Whatever their position, greater clarity would help a great deal to bring out the really important message that this letter contains.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Partly

Where applicable, are recommendations and next steps explained clearly for others to follow?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: History of health and healthcare.

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