

The price of certainty: How the politics of pandemic data demand an ethics of care

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Abstract

The Covid-19 pandemic broke on a world whose grip on epistemic trust was already in disarray. The first months of the pandemic saw many governments publicly performing reliance on epidemiological and modelling expertise in order to signal that data would be the basis for justifying whatever population-level measures of control were judged necessary. But comprehensive data has not become available, and instead scientists, policymakers and the public find themselves in a situation where policy inputs determine the data available and vice versa. This essay asks how we can live with what Amoore has termed ‘post-Cartesian doubt’ in situations of existential risk, and what kind of approach to science and data can answer the moral and human demands of a situation such as the Covid-19 pandemic. I suggest that science and policy could be able to control the pandemic better by addressing the sources of uncertainty and missing data not as gaps in the information landscape, but as individuals who are likely to be members of less-visible and less powerful groups including low-wage workers, the elderly, migrants, prisoners and others. This would shift both data use and policy toward an ethics of care, an embodied approach which asks what people need and how they behave in relation to each other, rather than how to manage population-level behaviour. This approach, I argue, is more appropriate for pandemic response than a utilitarian calculation of how many people each country should expect to lose as a result of the disease.

Keywords

Covid-19, data feminism, ethics of care, policy, public health, risk

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In 2011, historian of science Chunglin Kwa wrote:

Science will never again be the special province of a governing elite that claims to wield its authority in the service of culture and progress. Too many people have gained access to scientific information for there to be any way back. (Kwa, 2011: 275)

He may have spoken too soon: the Covid-19 pandemic broke on a world whose grip on epistemic trust (the faith that information circulating publicly is reliable) (Origgi, 2004) was already in disarray, and where people’s access to scientific information was being balanced by a chaotic online information environment that diminished trust in experts and government alike. The first months of the pandemic saw many governments publicly performing reliance on scientific, and specifically epidemiological,

expertise in order to establish that data would be the basis for justifying whatever population-level measures of control were judged necessary.

Comprehensive data, however, turned out not to be forthcoming. Instead irregular eruptions of scientific insight – such as the revelation that a policy focusing on controlling the movement of people showing Covid-19 symptoms will miss somewhere between 40 and 80% of infectious agents (Day, 2020) or the discovery that a vaccine may not fully resolve the pandemic due to

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varying degrees of immunity post-infection (Guardian, 2020c) – have failed to illuminate a clear path through the pandemic, leaving in their wake spaces for very different judgements on what can, or should, be done to control the spread of the disease. This irregularity and inconsistency has exposed epistemological fault lines in terms of policymakers' ability to deal with scientific uncertainty and illustrated how data can be used to perform public clarity of purpose without actually enabling those in authority to understand what is the best course of action.

The recent history of datafication has not fostered humility in the data science community. The Big Data paradigm (Kitchin, 2014) privileges positivist rhetorics of objectivity, rationality and certainty which in turn foster what José Van Dijck (2014) has termed 'dataism' – a belief that quantification produces truth, combined with trust in the agents who collect and interpret data. This paradigm does not align well with the epistemologies made possible by pandemic data, which arrives in fits and starts, full of holes, and is shaped by different national policies on public health and information. Covid-19, like all crises, has politics: it burrows deep into the faultlines of inequality, neglect and marginalisation; it exposes the under-funding of essential services and lack of attention to known risks. It rouses division, resistance and struggle, trapping governments around the world between the demands of politics and science: the cost of keeping the economy running can be measured in the daily loss of lives, while the cost of shutting down entire sectors can be measured in social unrest and economic collapse. The crisis is producing a different 'style of knowing' (Kwa, 2011) from conventional policymaking, one where the reciprocal relationship between policy inputs and evidence is downplayed and certainty is performed despite its human cost.

Any data available on the spread of the disease is a function of authorities' ability to capture and measure Covid-19's effects using the traces it leaves behind. Even death rates are uncertain (BBC, 2020). The inevitable bias towards local and policy-influenced data in modelling limits what can be understood about the side-effects of pandemic policy. Should people wear masks to reduce infections? If the question is being asked in a South-East Asian country, it is likely the data will produce the answer 'yes', while asking it in a European country for months produced the answer 'no', then shifted towards 'yes', the first based at least partly on culture and the second on broadening data collection beyond the local (Feng et al., 2020). Similarly, policymakers can pick and choose evidence to support or resist lockdown: the US underwent a wave of policy changes due to people at first perceiving lockdowns as inevitable based on epidemiological models and later resisting them based on conspiracy

theories that downplayed the risks of the disease and emphasised the economic models predicting recession. There, and around the world, the foregrounding of either epidemiological or social and economic data was determined by the presence of a social safety net and the corresponding economic risks to people's livelihoods.

Louise Amoore has asked how we can live with 'post-Cartesian doubt' in a time where algorithms are becoming a primary mode of evidence evaluation. This denotes a form of doubt that take into account both the human and the non-human (for example, machine and algorithmic rationales), as coinciding in ways that create new forms of uncertainty, 'opening onto an undecidable future, where one is permitted to ask new questions on the political landscape' (Amoore, 2019: 149). Amoore quotes physicist Richard Feynman: 'Permit us to question, to doubt, to not be sure... it is possible to live and not to know' (Amoore, 2019: 149). Her analysis of the Challenger shuttle disaster unpacks how authorities' decision-making on questions of life and death is based on percentages at each step of the process, rather than binaries. Yet the process of feeding unstable conclusions into authoritative decision-making disguises uncertainty as fact, producing binary outputs that paper over the reality of risk.

To answer Amoore's question as to how we can work with uncertainty as a feature rather than a bug, we may turn to the possibility of an ethics of care. First explored by Gilligan (1977), an ethics of care is an answer to the frequent lack of space for individual or group needs and idiosyncracies in theories of justice. It 'draws attention to problems of detachment or abandonment and holds up an ideal of attention and response to need' (Gilligan and Attanucci, 1988: 225). Like Amoore's idea of post-Cartesian doubt, an ethics of care is embodied: it takes into account what can be known of the person within the system and considers how this should shape what can, or should be done to resolve problems. It also visualises people as collectives, bound by responsibility for others, rather than agents rationally obeying predictable incentives. For instance, practicing an ethics of care in relation to data on the pandemic might involve actively seeking alternative sources of data on who are, or who become, invisible to official data collection under conditions of duress, and to how their behaviour responds to the needs of others as well as their own – migrant workers, the undocumented, the elderly in care homes and their families being some of those in the case of Covid-19. In the field of technology, feminist scholars have long pointed out the 'false binary between emotion and reason' (D'Ignazio and Klein, 2020: 77). They excoriate 'Big Dick data projects' which 'ignore context, fetishize size, and inflate their technical and scientific

capabilities' (p. 153). These disagreements about what constitutes reason and truth and how to know if a response to a problem is the correct one are brought into sharp relief by the Covid-19 pandemic.

Uncertainty has been at the heart of social policy during the pandemic. As well as perceived risk, actual risk of infection is influenced by people's social and economic situation. Both access to testing and exposure to the disease are correlated with socioeconomic status, occupation, location, age and many other factors across different countries including governmental economic priorities, national policy on information, and even the internal moderation policies of technology giants. The platform economy has been a less visible but globally involved actor in the pandemic, as social media algorithms first allowed misinformation to spread like wildfire and later were tamed by their proprietors to impose restrictions on how widely information could be shared, and what counted as reliable.

These competing truths warn that 'the data' on Covid-19 does not exist. Instead the pandemic has been characterised by emerging bodies of evidence which are being continually captured, shaped and reproduced in response to domestic policy needs, but which are inevitably replaced by other bodies of evidence, sometimes very fast. Examples include the research on the efficacy of hydroxychloroquine as a treatment for the disease (White, 2020) or a single expert's brief reversal of the WHO's position on asymptomatic transmission during early June (Guardian, 2020d). These bodies of evidence reflect underlying causal factors which can be understood using ground truth from social scientific inquiry, but this is a separate process from that of governing. Meanwhile, public discourse has skewed policy and research priorities (as occurred with the hydroxychloroquine hype in the US), causing further disruption of the ideal research-to-policy flow of information.

All these interacting forces create a situation where data, as an essential component of pandemic-related governmentality, becomes a reflection of the needs of policy, not the other way around. In some countries, a growing consensus on child infections and transmission (The New York Times, 2020) leads government to suspend reopening schools, while in others the authorities declare themselves convinced there is no risk of child-to-adult transmission. We see economically convenient data sometimes trumping inconvenient data, and that once a policy such as reopening schools or allowing public gatherings is put in motion it is easier to turn it into an experiment and watch what happens next, than to reverse it if new evidence emerges from other countries.

Real-time science is not usually on view to the public: people are used to seeing, as described by

Rubino (2000: 502), the 'idealised view of science as the vessel of certainty [that] holds out the promise of power: power over nature and power over our fellow human beings'. Instead the pandemic has revealed the scientific method in all its sociotechnical, Latourian chaos (Latour, 1987), where competing claims to truth clamour for attention and policymakers and their advisors must somehow convey certainty based on continually iterating knowledge.

It matters very much, however, what kind of process authorities follow when they learn from the data available. There is more to this collision between uncertainty and urgency than tradeoffs between economic and social policy. Where the rhetoric of certainty, usually an asset in politics, is continually undermined by changing knowledge and events, a policy that seems unassailable one week may turn out to pose unacceptable risks the next. How to govern with and through data in this information environment is a moral challenge that many authorities are not meeting. UK prime minister Johnson's initial attempt at a herd immunity policy, warning that 'Many families, many more families, are going to lose loved ones before their time' while declining to restrict public gatherings (Guardian, 2020b) and US president Trump's statement that the US would be 'doing well if it could hold the number of deaths down to 100,000' (CNN, 2020a) are examples of the real-time creation of policy-based evidence. These two statements are performative in that they determine the way evidence will be gathered and data will be read. First, 100,000 US deaths become a desirable target (after previous official best-case scenarios of 50,000 and then 75,000 (CNN, 2020b)), and it becomes permissible to gather data in ways that will shape the number of fatalities to fit with that total (for example by counting, or not counting, deaths of the elderly in care homes or younger people outside hospitals). Second, by referencing particular epidemiological forecasts the statements reify those models' predictions, despite their doubtful and evolving nature. This makes setting a political boundary for how many may die (not how many will die) an act of necropolitics (Mbembe, 2001) – an orienting of state power and policy to shape the mortality of a target group or population – that cites data and models as if they, rather than policymakers' use of them, determined the risk to life. This kind of claim to political certainty can even be a weapon: In India, early in the pandemic the authorities oriented their testing resources towards particular Muslim groups in order to create a dataset showing they were a main source of infection (AlJazeera, 2020).

The overlap between political control and disease control in many countries has created governmental openness to technological solutions to the pandemic,

and as a result building the capacity to measure and track have often been emphasised over the ability to understand exactly what has to be measured and tracked. The pandemic has so far put public authorities at the mercy of vendors piling in to sell repackaged applications as Covid-relevant technologies: examples include glasses that assess people's body temperature and can link to facial recognition systems to track anyone with a fever (Newsweek, 2020), but which focus attention away from the majority of people believed to be asymptomatic, or the proposed sewage-testing system that indicates when people in a neighbourhood are infected and about to get sick (Peccia et al., 2020) and which, the authors note, is 'is particularly useful for low and middle-income countries' (p. 6). In contrast an ethics of care might focus proportionally more resources on preventing than on tracking infection, and in order to direct those resources might look at how people are represented by data in order to understand how data can be improved to prevent the spread of disease. Many medical specialists, public health experts and scholars in governance-related disciplines have taken on the task of explaining where evidence is missing, where data is misreported or misinterpreted, and where certainty is unwarranted. These specialists start from the same insights as Fotopoulou, when she observes that 'data practices are material and embodied, as they involve human labour and power relations' (Fotopoulou, 2019: 3), and that to understand 'the data', we need to understand both the observer and the observed.

If, using Fotopoulou's logic, we look at the gaps and uncertainties in the data being used to track the pandemic, we see they map onto the groups that are often subjects of inquiry in both feminist theory and the ethics of care. Women, whose labour is more often invisible and informal; prisoners; the elderly, who live largely out of sight of the powerful; low-income workers in hard and dangerous jobs; migrants; the homeless; those who are sick; those who work in hospitals, schools, shops and factories, driving taxis and delivering food. These are people who either cannot get out of the way of the pandemic, or who are not permitted to because their work is too essential. These groups embody the uncertainty of pandemic data through their informal or invisible labour and their absence from the economic and healthcare maps. Those with responsibilities of care and the recipients of that care form important chains of transmission of the pandemic, but the groups involved exist on the margins of data collection. Depending on the country many are undocumented or unregistered, working informally, or invisible in care homes, camps or prisons. Many of the most vulnerable are minorities, for intersecting reasons including discrimination in the labour market, limited

access to healthcare and monitoring, lack of access to safety in all dimensions. The poor and marginalised are not allowed or are unable to follow the rules: they do not control their hours of work, how they travel, their ability to wash their hands, their ability to self-isolate. They are exposed to pesticides and smog, they are evicted, deported or imprisoned more readily, and if they make it to hospital, they are less likely to be believed by doctors (Institute of Medicine (US), 2003).

The uncertainty of the picture data provides, and particularly the new, born-digital sources of data, has always been proportional to the status and power of those it describes. Worldwide, ground truth on issues of economic wealth, public health, and even spatial location is more true for some than others. This is because more, and different, data is collected on some than others (Dalton et al., 2016). It was not until it became apparent that ethnic minorities in the UK were dying of Covid-19 at disproportionately higher rates than the white majority that it was proposed that death certificates note ethnicity (Khan, 2020) – a process comparable to the glacial policy shift in the US toward officially documenting the killing of black and minority ethnic people by law enforcement (Reuters, 2018).

These unequal dynamics of data collection mean that the sources of uncertainty and missing data are often particular groups: those whose selves – or whose labour – are invisible or underpriced and whose autonomy and visibility is limited by the same structures that allow others to self-isolate and 'flatten the curve' of the disease. This has implications for technical measures proposed to 'solve' the pandemic through data, such as tracking apps. Like epidemiological data, app data on contacts and infections is dependent on a web of other datasets, on the ability to measure accurately, and even on the ability to define what should be measured (BBC, 2020). 'If only the virus would spread in ways that can be detected using the app' (Babones, 2020), and submit to the technology, the job of policy would be significantly easier.

When a group of technical and business experts (Oliver et al., 2020) explain the various ways in which mobile phone data can track people as groups and individuals to help authorities understand people's movements and behaviour, the differences in ground truth, as well as the politics of data, become salient. The 'truth' data can provide is only as good as the authorities' political will to use it – if a government uses aggregated data to identify gatherings where infection may occur, it may choose to identify gatherings on a political rather than a public health basis (AFP, 2020), rendering the data meaningless as a tool for prevention. Similarly, if mobile-based contact tracing is used to substitute for more costly but more accurate

human contact tracing which asks people about the nature and detail of their contact with others, blunt proxies for ground truth on location, interactions with others, and daily activities become the guide for behavioural insights and risk perception (Babones, 2020). The rational subject is the enemy of public health: apps that read location rather than behaviour give the illusion that people can choose how they mitigate the risk of infection, and in turn, the potential for blaming those who do not, or cannot, behave accordingly.

In contrast, an ethics of care has the advantage of centring the stochastic reality of behaviour – the way in which less-visible groups also tend to be those who conform less to the norms of behaviour on which data analytics are predicated. Migrant workers make choices based on transnational rather than local needs; people will disobey rules and expose themselves to infection in order to care for sick family members; refugees will continue to travel towards places with higher rates of infection due to the pressure of risk and violence. Realities such as these do not fit with behavioural modelling and will make nudging strategies by policymakers ineffectual, so that an ethics of care that takes into account the embodied nature of risk and decision-making may also challenge policy to reconcile normative and situated modes of knowing. Such a process would align with de Ridder's argument (2014) that some forms of scientific knowledge are inherently collective and can only be built through iterative processes of discovery and structured communication amongst experts. Similarly, the kind of policy knowledge that can adequately answer a pandemic cannot be extracted from a single scientific perspective, by 'trusting the science'. Instead it must be continually adjusted: the process of turning knowledge into policy must be structured so that it can be pushed off balance by evidence of what was previously invisible.

There is not only a moral reason to take account of different situatedness and needs, and to think across national and economic contexts, there is a very practical one too. From the standpoint of those who are, or who are rendered, most vulnerable to the pandemic, a policy position that attempts only to balance general loss of life with economic pressures is an existential threat. From the broader societal perspective, however, it also threatens our ability as a world to combat the pandemic. If policy responses around the world cannot take account of the vulnerability of groups or response systems, policymakers are blinded to the true course of the pandemic and cannot combat it effectively. If the virus lives on amongst the poor and marginalised, everyone on earth is at risk.

A perspective that centres care as an awareness of embodied individual experience and needs, in contrast,

separates out the value of human life from economic value (Eubanks, 2018). It implies a mode of risk evaluation informed by kindness and inclusivity. Such a perspective values all lives equally (something that has become genuinely controversial during the pandemic) rather than calculating life-years of potential economic activity or proposing that the elderly sacrifice their lives for the stock market (Guardian, 2020a). Instead of a binary of control/loss of control, it starts from the practice of medical decision-making, where not only knowledge but communication and consent are required for action. Angela Merkel's March speech to the German people (dw.com, 2020) stands out as an example of a leader calling on an ethics of care to support and legitimise science-based policy: she stressed that 'we are a community in which every life and every person counts', and that 'consideration for one another' is the way through a pandemic where scientific knowledge will continually fall short. Merkel emphasised explanation and transparency, and noted that policy understanding was evolving and would change.

An ethics of care demands that science-based policy reorient regularly from the notion of the majority to that of the collective. Seeing people and groups rather than populations offers more possibilities for taking particular vulnerabilities into account, and thus for avoiding new clusters of infection. Orienting data collection and attention to how the majority is composed of minorities – to the idea of a superdiverse social world (Meissner and Vertovec, 2015) – means orienting towards the experiences of children, the elderly and the sick, to different ethnic, religious and gendered normalities, to the economically disadvantaged and the socially excluded. This in turn makes possible more detailed understandings that can explain and inform far better than data about the illusory majority at the centre of the normal curve. If authorities decenter the idea of rational, or predicted, behaviour, along with the idea that authorities should seek to nudge and manipulate rather than inform and persuade, this may also have the effect of bringing policy and its discourses closer to the lived reality of the pandemic, and in doing so increase epistemic trust (Ioannidis, 2020). Statistical normality is abnormal – it is the minority position. There is no 'herd', only a mosaic of different vulnerabilities. Until policy analysts can take this into account methodologically, and orient toward a care perspective, we remain at risk from the domestic unknown.

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