SPECIAL ISSUE: TRANSLATIONAL BIOETHICS



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Providing ethics advice in a pandemic, in theory and in practice: A taxonomy of ethics advice

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Abstract

The pandemic significantly raised the stakes for the translation of bioethics insights into policy. The novelty, range and sheer quantity of the ethical problems that needed to be addressed urgently within public policy were unprecedented and required high-bandwidth two-way transfer of insights between academic bioethics and policy. Countries such as the United Kingdom, which do not have a National Ethics Committee, faced particular challenges in how to facilitate this. This paper takes as a case study the brief career of the Ethics Advisory Board (EAB) for the NHS Covid-19 App, which shows both the difficulty and the political complexity of policy-relevant bioethics in a pandemic and how this was exacerbated by the transience and informality of the structures through which ethics advice was delivered. It analyses how and why, after EAB's demise, the Westminster government increasingly sought to either take its ethics advice in private or to evade ethical scrutiny of its policies altogether. In reflecting on EAB, and these later ethics advice contexts, the article provides a novel framework for analysing ethics advice within democracies, defining four idealised stances: the pure ethicist, the advocate, the ethics arbiter and the critical friend.

KEYWORDS

Covid-19, ethics advice, ethics-washing, public interest, translational bioethics

1 | INTRODUCTION

The Covid-19 pandemic was a public health emergency. The novelty, range and sheer quantity of the ethical problems that needed to be addressed urgently within public policy were unprecedented. While fair allocation of scarce healthcare resources had been much studied within philosophy and bioethics, the nature of the scarcities during the pandemic provided significant new challenges. Some scarcities were of kinds that had not been discussed much before (e.g., personal protective equipment and ventilators). Other kinds of scarcities

such as staff time became salient in new ways, as health systems struggled to meet significantly increased patient need with a depleted clinician workforce. Moreover, there was a range of questions that few had thought about systematically before, such as the use of contact tracing apps, or whether, and if so when, vaccine passports should be used.¹

¹Yellow Fever certificates were of long standing, but did not provide a helpful analogy to Covid-19, due to differences between the diseases in access to vaccines and vaccine effectiveness and in disease vectors. For further analysis, see Ada Lovelace Institute. (2021). Checkpoints for vaccine passports. https://www.adalovelaceinstitute.org/report/checkpoints-for-vaccine-passports/

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These novel circumstances required high-bandwidth two-way transfer of insights between academic bioethics and policy. Inspired by the idea of translational medicine, which focuses on improving the processes by which insights generated at the laboratory bench lead to benefits for patients, we describe the attempt to improve the transfer of insights between theoretical ethics and real-world ethical decision-making as translational bioethics. High-quality translational bioethics requires attention to context: it cannot be presumed that the factors relevant to translation of insights from more theoretical to more practical contexts will be uniform. Academic bioethicists in states such as the United Kingdom, in which ethics advice for policy had previously been ad hoc and informal, faced different translational challenges from those in states such as Germany or Switzerland, which had long-standing and well-entrenched National Ethics Committees

This paper is grounded in the context of ethics advice in the United Kingdom and develops as a case study the brief career of the Ethics Advisory Board (EAB) for the NHS Covid-19 App. This case study shows both the difficulty and the political complexity of policy-relevant bioethics in a pandemic and how this was exacerbated by the transience and informality of the structures through which ethics advice was delivered.

The paper then analyses how and why after EAB's demise, the Westminster³ government increasingly sought to either take its ethics advice in private or to evade ethical scrutiny of its policies altogether and how this made the task for translational bioethics even more difficult. It argues that this closed approach to translational bioethics was itself unethical, falling short in ways that are neither explained by the inherent difficulties of applying ethics frameworks to public policy nor the additional difficulties introduced by the pandemic. While the empirical analysis focuses on a particular geographical context, the paper builds from this to a typology that has implications for ethics advice for policy in liberal democracies more generally. The typology distinguishes four idealised roles: the pure ethicist, the advocate, the ethics arbiter and the critical friend. We examine why public institutions prize ethics arbiters and critical friends and why problems occur when there is disagreement or confusion about which role individuals are adopting.

2 | POLITICAL ACCOUNTABILITY AND ETHICAL JUSTIFIABILITY

Within a democracy, political accountability is crucial: it needs to be clear where and by whom decisions are made and to whom those making the decisions are accountable. Chains of political accountability end with the executive—those ministers who form the government, and have the task of deciding overall policy direction, and making high-level decisions. Policy is developed and implemented by a very large number of non-politically aligned public servants, who are accountable to ministers. Depending on ministerial style and broader norms, the relationship between ministers and public servants accountable to them may be either combative or consensual. 5

Ministers need to combine the evidence provided to them by public officials with a set of political priorities and (often implicit) ethical values to make decisions. The relationship between democratic accountability and the ethical justifiability of policies is complex. Ministers may understandably frame the question of what ethical values policy should aim to enact, and how it should balance them, as something that their democratic mandate empowers them to decide. Opening up the quality, rigour and wisdom of the ethical thinking that underlies their policy direction to sustained and impartial scrutiny would not only tend to constrain their executive power but could also easily lead to a loss of face, if, for example, a flagship government policy needed to be abandoned because rigorous scrutiny revealed that it was ethically indefensible. Moreover, ministers are incredibly busy, and the nature of the fire-fighting and quick decisions inherent in the role is not conducive to developing ethical frameworks that articulate and reconcile the different ethical considerations at play in the policies that their government departments introduce.

Public institutions can develop the capability for rigorous ethical scrutiny of government policy, but their ability to do so is constrained by their role and considerations of democratic legitimacy. There would be obvious problems of democratic legitimacy if those working in public service frequently undertook freelance ethical thinking and, for example, refused to implement policies decided on by democratically elected politicians because they believed these policies to be unethical. Hence, while public servants often have significant room for manoeuvre in deciding how the policy is developed and implemented,⁶ overall policy and implementation must nonetheless be in line with the government's intentions.⁷

²The literature on translational medicine has long made clear that translation needs to be two-way and that simple linear models in which insights only flow from the 'bench' to the 'bedside' are insufficient. See Marincola, F. M. (2003). Translational Medicine: A two-way road. *Journal of Translational Medicine*, 1(1), 1. The concept of translational ethics was introduced by Alan Cribb in Cribb, A. (2010). Translational ethics? The theory-practice gap in medical ethics. *Journal of Medical Ethics*, 36(4), 207–210. While Cribb's initial article was sceptical about whether translational ethics is a useful addition to the bioethics lexicon, the idea was taken up with greater enthusiasm in Bærøe, K. (2014). Translational ethics: An analytical framework of translational movements between theory and practice and a sketch of a comprehensive approach. *BMC Medical Ethics*, 15(1), 71; Wilson, J. (2014). Embracing complexity: Theory, cases and the future of bioethics. *Monash Bioethics Review*, 32(1–2), 3–21.

³Health in the United Kingdom is a devolved matter. The Scottish Parliament, Welsh Parliament and Northern Ireland Assembly have responsibility for health policy in their respective countries. As far as health is concerned, the authority of the Westminster parliament is confined to England, even though in non-devolved areas such as defence, it makes policy for the whole of the United Kingdom.

⁴Depending on the structure of the democratic arrangements, these public servants may be formally designated civil servants or, as often happens in the United Kingdom, be employed in nondepartmental public bodies or executive agencies.

⁵Devine, D., Boswell, J., & Smith, J. (2022). *Managing as a minister*. Institute for Government. https://www.instituteforgovernment.org.uk/publications/managing-minister

⁶For a classic analysis, see Lipsky, M. (2010). Street-level bureaucracy, 30th Anniversary Edition: Dilemmas of the individual in public service. Russell Sage Foundation.

⁷The U.K. Civil Service Code makes clear that civil servants must not 'frustrate the implementation of policies once decisions are taken by declining to take, or abstaining from, action which flows from those decisions'. (Her Majesty's Government. (2015). *The Civil Service Code*. Retrieved June 24, 2022, from https://www.gov.uk/government/publications/civil-service-code/the-civil-service-code.)

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Political accountability is thus clear, but responsibility for the ethical justifiability of policies that are developed and implemented is less clear. Unless steps are taken to avoid this, responsibility for ethical justifiability may fall uncomfortably between the two stools of politicians (who own the high-level policy direction, but may not fully understand the detail) and public servants (who understand the detail, but may have limited ability to ameliorate ethical problems that are revealed by the policy's effects in practice).

This raises an important set of questions for academic bioethicists who want to contribute to ethical deliberation within policymaking. This challenge is distinct from, and significantly more difficult than, the challenge for academic scientists who want to influence the policy process through the provision of scientific evidence. Scientific evidence on the effectiveness of different means to politicians' ends appears to be much easier to assimilate to and harness within politicians' priorities than expert ethical scrutiny. This is because expert ethical scrutiny may challenge politicians' ability to frame the policy issues and construct publics and may also raise questions of democratic legitimacy by stepping into the territory of 'political judgement'.

The normative structure of democracy itself places some limits on the ways in which ethical values should be brought into the policy process. We can distinguish between two potential models for the bioethicist in public policy, distinguished by how the bioethicist situates themselves relative to broader public values. First, bioethicists could take their role to be to argue for their own value judgements within the decision-making process, regardless of the extent to which these value judgements are widely shared within society as a whole. Where this model is used as the basis for policy-relevant translational bioethics, it faces significant challenges of democratic legitimacy, particularly if the bioethicist's approach would run counter to some deeply held public values. Even if bioethicists did have genuine ethical expertise, it is not clear that it would be appropriate for democratic decision-making to defer to their ethical judgements.⁸

Second, bioethicists could take their role in public policy to be mediated by and responsive to the values held by different publics and to focus on attaining a shared understanding of the common good or public interest. This might, for example, involve ensuring that some values and voices are not inappropriately sidelined in deliberation or suggesting how competing values can be reconciled in the most coherent and fruitful way. Given the difficulties in reconciling the first model with fundamental assumptions of democratic decision-making, the second model has been much more favoured for mobilising philosophical and ethical expertise within democracies. Section 7 provides a taxonomy of four different approaches to ethics advice within the public sphere, depending on whether (1) the advice-giver makes a recommendation about what is to be done in response to a specific policy question and (2) whether

the advice is delivered from the perspective of the public interest (see Table 1).

How to provide ethical scrutiny of public policy that is both democratically legitimate and robust has been addressed at an institutional level in many countries by the establishment of a National Ethics Committee. Such bodies have a democratic remit to perform ethical scrutiny and provide ethics advice, and the executive may also have a legal duty to seek this advice and have regard to it. This provides a way of bringing ethical scrutiny into the heart of government policymaking, while also ensuring democratic accountability.

The United Kingdom does not have a National Ethics Committee. The Nuffield Council on Bioethics (NCOB) is the closest analogue and represents the United Kingdom in this function at international meetings of National Ethics Committees. NCOB has seen many successes in policy-relevant bioethics-for example, its 2012 report on Novel Techniques for the prevention of mitochondrial DNA disorders was influential in giving U.K. lawmakers the confidence to make the United Kingdom the first country in the world to introduce regulations allowing mitochondrial DNA donation. 10 However. as its former chair Professor Sir Jonathan Montgomery noted in 2017, NCOB has no statutory basis, and hence 'no authority merely by virtue of the position it holds'; what authority NCOB has is 'relational' and 'based on its reputation'. 11 During the pandemic, the Westminster government was not under a legal duty to take ethics advice from NCOB or any other body. This made it possible for it to be selective in the ethics advice it sought and to do so only on issues of its choosing. This raises questions about how ethical scrutiny was incorporated into Westminster policymaking during the pandemic, and whether a different approach could have improved the ethical quality of decision-making, while remaining democratically legitimate and congruent with existing structures and norms, as the next sections explore.

3 | ETHICS ADVICE AND THE PUBLIC INTEREST

It is no more tenable for governments to act on the basis of values that have no resonance with broader publics than it is for philosophers or bioethicists to provide policy advice on the basis of such values. Moreover, political decision-making also faces the question of how to reconcile the tensions that occur in practice between competing values—for example, between respect for individual liberty and the need to protect the most vulnerable.

⁹The World Health Organization maintains a list of National Ethics Committees. World Health Organization. (2022). *National Ethics Committees*. Retrieved July 28, 2022, from https://apps.who.int/ethics/nationalcommittees/nec.aspx

¹⁰See Nuffield Council on Bioethics. (2015). UK approves regulation on mitochondrial DNA donation. https://www.nuffieldbioethics.org/news/uk-approves-regulation-on-mitochondrial-dna-donation

¹¹Montgomery, J. (2017). The virtues of National Ethics Committees. Hastings Center Report, 47(S1). S24–S27. at p. S24.

TABLE 1 A typology of ethics advice for public policy.

Typology of ethics advice for public policy		
	Partial perspective	Public interest perspective
No recommendations	The Pure Ethicist	The Ethics Arbiter
Recommendations	The Advocate	The Critical Friend

Source: Adapted from Pielke's typology of science advice.

Specifying how values should, and should not, be used within democratic policymaking requires the positing of a stance from which public values can be articulated and reconciled.

Concepts such as that of the common good and the public interest, while inherently indeterminate and open-ended, serve to help identify both the wrong kinds of reasons for democratic decision-making and also function proleptically as a goal to be filled out in context. We focus here on the public interest, given its centrality to the U.K. government's accounts of the duties of public officials. While, as we shall see, the details of what the public interest entails may be specified differently in different contexts, it always requires a particular orientation towards acting in ways that are open and impartially justifiable:

the individual citizen may be obligated to obey governmental actions which conflict with his interests, but government is expected to justify its decisions and actions in terms of a standard appropriate to the position which requires those decisions, its position as a public agent. The function of the concept of 'public interest' is to provide such a standard, and its logic corresponds to that function.¹²

At a minimum, and most obviously, acting in the public interest requires adopting a perspective different from one that we usually adopt in day-to-day life. It requires separating one's private interests, which are of course legitimate in their own sphere, from the perspectives and attitudes one should take when acting in a certain role on behalf of the public. So, for example, there is nothing wrong in trying to advance the interests of one's children or friends in one's life outside work, but this is not something that someone should be aiming to do in so far as they are acting in a public role. Interests and relationships that might plausibly interfere with acting solely on the basis of the public interest need to be declared and resolved.¹³

In the United Kingdom, all of those in public life, including politicians, civil servants, those who work in nondepartmental public bodies, and we might add philosophers and bioethicists in so far as they participate in an ethics advisory board for a public body, are supposed to adhere to the Nolan Principles of Public Life. ¹⁴ The first Nolan principle is Selflessness, namely, that 'Holders of public office should act solely in terms of the public interest'. ¹⁵ The other six Nolan Principles—of Integrity, Objectivity, Accountability, Openness, Honesty and Leadership—go some way towards fleshing out what it means to act solely in terms of the public interest, but do not narrow down the kinds of values, and weightings of values, that are required by acting in the public interest.

The idea of public interest is thus deliberately left somewhat indeterminate. This guards against the risk of pre-specifying a rigid answer to complex cases in advance of having full knowledge of the relevant circumstances of the case and also allows due deference to the fact that the content of the public interest is determined in part by the results of the democratic process. As the bare idea of public interest is insufficient by itself to provide determinate guidance on what is to be done, it is useful for government departments and institutions to design domain-specific value frameworks and involve in this process not only publics but also those with relevant expertise, including philosophers and ethicists. Examples might be the NHS Constitution, the Office for National Statistics' Code of Practice for Statistics and the government's Data Ethics Framework. 16 Articulating a value framework that expresses and constrains the otherwise indeterminate idea of the public interest will be particularly important where the stakes are high, and the decisions to be taken will lead to losers as well as winners.

To the extent that a government department or a public body has such an ethical framework, there would usually be a strong presumption that those who provide it with ethics advice should do so in ways that draw on and are compatible with this framework. One implication is that bioethicists who are asked to provide ethics advice to politicians or public bodies are often asked to answer questions that have been defined by others (perhaps in a way that seems too narrow) and to do so with respect to a set of values that they might, in other contexts, wish to critique. For example, a government's value framework may presuppose that supporting its domestic life sciences industry is of vital strategic importance. This may profoundly shape the questions that it seeks ethical advice on in healthcare resource allocation, perhaps focusing only on how to make access to expensive novel cancer drugs fairly available within the public system, rather

¹²Flathman, R. E. (1966). The public interest: An essay concerning the normative discourse of politics (p. 8). Wiley.

¹³The idea of public interest is important within law, public policy and the public sphere more generally, but it is used in slightly different ways in different contexts. For a good overview, see Cochrane, L., & Morison, J. (2018). Public interest. In C. Leanne & M. John (Eds.), Max Planck encyclopedia of comparative constitutional law. Oxford University Press.

¹⁴Committee of Standards in Public Life. (1995). The seven principles of public life. Retrieved June 19, 2022, from https://www.gov.uk/government/publications/the-7-principles-of-public-life/the-7-principles-of-public-life-2 The Nolan Principles apply to 'all those who are elected or appointed to public office, nationally and locally, and all people appointed to work in the Civil Service, local government, the police, courts and probation services, non-departmental public bodies (NDPBs), and in the health, education, social and care services'. (Ibid.) Ministers additionally must adhere to the Ministerial Code.

¹⁶For a worked example of how the values expressed in the NHS Constitution could be mobilised to help specify how to determine when sharing of NHS data with commercial companies is in the public interest, see Wilson, J., Herron, D., Nachev, P., McNally, N., Williams, B., & Rees, G. (2020). The value of data: Applying a public value model to the English National Health Service. *Journal of Medical Internet Research*, 22(3), e15816. https://doi.org/10.2196/15816



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than whether the unit of resource might be put to better use within the health system.

Such limitations do not by themselves make the work of academics who provide ethics advice in the context of a preshaped process, and in the light of a set of institutional values, ethically problematic. As we have seen, some such constraints are in fact required by a commitment to democratic decision-making. And when such frameworks act as independent points of reference for ethical reflection and decision-making, they can function to coordinate the activity of a range of stakeholders who are interested in providing ethical input to some domain of public policy. We discuss when constraints on ethics advice do become problematic—in short, 'ethics-washing', below.

Bioethicists who are outside of the formal process of advice provision, but nonetheless want to make a difference to the overall policy direction or to a particular decision face an even more difficult prospect. Lacking knowledge of the constraints on what would count as 'good' ethics advice in the context, they are unlikely to produce analyses that are deemed relevant to the question at hand by policymakers.

4 | INTEGRITY, ETHICS-WASHING AND ETHICS ADVICE

There are circumstances in which it would be ethically tainting, or otherwise ethically troubling, to be involved in the provision of ethics advice. Many examples where there seems to be something ethically questionable about providing ethics advice involve what is known as 'ethics-washing'. ¹⁷ In ethics-washing, an organisation or institution that does not in fact have a very deep commitment to acting ethically publicises the fact that it has taken ethics advice, as a way of giving the impression that what it is doing is ethically justifiable. ¹⁸

There is a range of cases in which what is arguably ethics-washing can occur in the public sector—some more ethically troubling than others. At the less ethically challenging end of the continuum, an organisation or institution may make a good-faith attempt to act in the public interest, but for one reason or another, its engagement with ethical reasoning comes late in the day and ends up being, in effect, tokenistic. Perhaps the policy is developed on the basis of a somewhat limited understanding of the public interest, and unintentionally excludes some perspectives until it is too late to change the policy in a deep way. In such cases, ethics can

come to be perceived as an afterthought and end up having little impact on the final shape of the policy, even though those implementing the policy genuinely intend that the policy advances the public interest.

Ethics-washing can also occur in a more strategic way—for example, by deliberately seeking ethics advice only on a narrow subset of the questions raised by a controversial new technology, and thus giving the impression of robust ethical scrutiny while avoiding troubling questions about the ways in which the technology might disproportionately impact marginalised groups. In such cases, even if the ethicist's advice is sound within the limited range of responses allowed, it might nonetheless contribute in an ethically problematic way to the success of a policy that is overall ethically unjustifiable.

At the most challenging end of the spectrum, there may be genuine uncertainty about whether those framing and enacting the policy have acting in the public interest as their main goal. For example, the policy may appear to be, to a significant degree, designed as it is to benefit associates of the policymaker, or to generate headlines (without the intention to carry the policy out), or to reduce access to information that would allow citizens to hold the government to account. In such cases, being involved as an ethicist, while being asked to overlook or to ignore the possibility of failures of integrity in public office, is particularly likely to involve a sense that one's own integrity is on the line.

Of course, when in the thick of things as ethicists were at the height of the pandemic, it may be difficult to determine to what degree, if at all, ethics-washing is occurring. By way of illustration, we examine the work of the Ethics Advisory Board for the NHS Covid-19 App in 2020.

5 | THE ETHICS ADVISORY BOARD FOR THE NHS COVID-19 APP

The idea of smartphone-enabled automated contact tracing was completely new when an NHS Covid-19 app was proposed in March 2020. Deploying such an app at sufficient scale to make a significant difference to the outcome of the pandemic raised a number of complex questions about privacy, surveillance and inclusion. An Ethics Advisory Board (EAB) was convened in early April 2020 at the request of the Department for Health and Social Care (DHSC), and one of us (Wilson) was asked to represent the National Data Guardian on the Board.¹⁹

The account that follows draws on material that has since been placed into the public domain via EAB's minutes and final report, ²⁰ subsequent published interviews with panel members, ²¹ media reports and a range of contemporaneous notes.

When EAB was first convened, the government's view seemed to be that it would be the app rather than anything else that would bring

¹⁷Wagner, B. (2018). Ethics as an escape from regulation: From 'ethics-washing' to ethics-shopping? In E. Bayamlioğlu, I. Baraliuc, L. Janssens, & M. Hildebrandt (Eds.), Being profiled: Cogitas Ergo Sum: 10 years of profiling the European citizen (pp. 84–89). Amsterdam University Press.

¹⁸Google's short-lived Advanced Technology External Advisory Council (ATEAC), which was launched in 2019 to advise on the complex challenges posed by Al projects, is often cited as an example of ethics-washing. As the personnel and the powers of ATEAC were publicised and scrutinised, it became clear that neither the Council's personnel nor its ability to steer the direction of Google's research were sufficient to maintain public confidence. ATEAC was abandoned shortly after launch. For further discussion, see Johnson, B., & Lichfield, G. (2019, April 6). Hey Google, sorry you lost your ethics council, so we made one for you. MIT Technology Review. https://www.technologyreview.com/2019/04/06/65905/google-cancels-ateac-ai-ethics-council-what-next/

 $^{^{19}\}mathrm{Dr}$ Alan Hassey also attended EAB on behalf of NDG. A full list of EAB members is provided in EAB's final report.

²⁰Ethics Advisory Board (EAB). (2020). Report on the work of the Ethics Advisory Group to NHSx on the COVID19 contact tracing app. https://covid19.nhs.uk/pdf/ethic-advisory-group-report.pdf

²¹Samuel, G., & Lucivero, F. (2021). Bringing ethics into governance: The case of the UK COVID-19 contact tracing app. *International Journal of Health Governance*, 27(2), 180–193.

the Covid-19 outbreak under control in the United Kingdom. This priority extended to timing too: the plan was that the app would launch before a national testing strategy and before manual contact tracing had restarted.²² Given this policy context, the major design decisions initially taken about the app become intelligible: as the final EAB report puts it,

the strategy of leading with an App that (a) centralised the proximity information that it had collected, and (b) triggered alerts to self-isolate on the basis of reported symptoms rather than test results, might have looked like the only plausible option from a public health perspective.²³

Both the decision to adopt a centralised model and to trigger alerts on the basis of self-reported symptoms were ethically controversial, and both were dropped before the app finally launched.²⁴ While these decisions about app design followed from the government's strategy at the time, it was obvious to informed commentators that the strategy itself was very different from that recommended by the WHO, and different also from that followed in countries in which Covid had been brought under control. The WHO-recommended approach was to focus on virological testing, manual contact tracing and isolation.²⁵ The Westminster government's strategy presupposed that the outbreak could be brought under control without widespread testing or manual contact tracing through the use of the app alone. This created a degree of tension about the nature and scope of the ethics advice being sought.

As was discussed in EAB's first meetings, the app would be able to play the role envisaged for it in the strategy only if a number of demanding, but unproven, assumptions all held simultaneously: (1) the vast majority of those who had phones capable of running the app downloaded it, (2) the app worked well at a technical level in detecting the presence and proximity of other phones, (3) those who downloaded the app continued to interact with and to use the app over a period of months and (4) a high percentage of those who received alerts asking them to self-isolate complied.²⁶ However,

given that EAB were led to believe that the app 'would be the leading pillar of a national strategy for Covid recovery, and would be rolled out nationally within a few weeks',²⁷ advising that the strategy as a whole was deeply flawed would not only have been deeply unwelcome to DHSC but was also outside of EAB's terms of reference.

EAB's initial analysis and conversations made clear that maintaining high levels of public trust in the project was a necessary condition for the success of the strategy. Without sufficient levels of trust, not enough people would be willing either to download the app, to continue using it, or to act on its recommendations. Maintaining trust would in turn require that the project communicate in a way that established its trustworthiness. The app's proposed reliance on self-reported symptoms rather than test results created difficulties for trustworthiness, and was picked out as central not only by EAB but also by the initial focus groups run with members of the public.²⁸ Moreover, DHSC was far too slow to publicly articulate a rationale for why a centralised model was being adopted rather than a decentralised model. This allowed a narrative to take hold that a disproportionate amount of data would be collected—a narrative that was articulated ably and energetically by advocates for decentralised models and proved corrosive of public trust.²⁹

EAB was dissolved by the government in July 2020, after a number of high-profile leaks from its meetings, and some EAB members giving interviews to the press indicating that they were not happy with the accuracy of the information provided to the Board or with various aspects of the app design and testing.³⁰

As EAB's final report explained, the strategy for controlling Covid changed from a 'tech project' to a 'large-scale health project, in which tens of thousands of people are employed'³¹ in the 3 months between EAB's first and last meeting. The failure of the initial strategy allowed a realignment to what could perhaps have been accepted initially, namely, that what was required was an integrated public health strategy, which was deeply integrated into broader NHS infrastructure. The app was then reframed as a potentially useful add-on to the Test and Trace strategy that was being led by testing and manual contact tracing.³²

When EAB was dissolved, there was no firm commitment to launch the app, but merely an aspiration that it would be launched for the winter if its value proposition could be made sufficiently strong. The app itself was then completely redesigned by a different team, using a decentralised model that was made possible by an API developed in common by Apple and Google, and was formally launched at the end of September 2020.³³ The belated pivot to a decentralised model, after two months of arguing

 $^{^{22}\}mbox{EAB},$ op. cit. note 20, at p.10.

²³lbid: 10.

²⁴The decision to use self-reporting was driven by lack of testing capacity. It was ethically controversial, as what little research there was indicated that individuals were highly unreliable judges of whether they had Covid-19. Moreover, self-reporting meant that individuals could cause others to be required to self-isolate by reporting symptoms maliciously or frivolously. Given that those who were being required to self-isolate would be aware of the unreliability of the information that led to the alert, EAB thought it likely that compliance might be low. Use of a centralised model was ethically controversial, as contact tracing could also be done effectively in a privacy-preserving manner through a decentralised model. So the centralised approach was vulnerable to the charge that it collected far more data than was necessary. One key reason that the centralised model was proposed, which was not publicly acknowledged, was that only a centralised approach would allow the high levels of noise introduced by self-reporting to be reduced to acceptable levels via the use of sophisticated analytics.

²⁵World Health Organization. (2020). WHO Director-General's opening remarks at the media briefing on COVID-19–16 March 2020. Retrieved February 26, 2023, from https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19–16-march-2020

²⁶See the EAB minutes for 2 and 9 April 2020, in ibid: 46–49.

²⁷Ibid: 10.

²⁸EAB minutes, 9 April 2020, in ibid: 47-49.

Jbid: 13

³⁰See Samuel & Lucivero, op. cit. note 21; Samuel, G., & Lucivero, F. (2022). Framing ethical issues associated with the UK COVID-19 contact tracing app: Exceptionalising and narrowing the public ethics debate. Ethics and Information Technology, 24(1), 5. https://doi.org/10.1007/s10676-022-09628-z

³¹EAB, op. cit. note 20, p. 11.

³²EAB, op. cit. note 20, pp. 10-11.

³³For more on the timeline, see Downey, A. (2020). *Timeline: What happened with the NHS Covid-19 app.* https://www.digitalhealth.net/2020/04/timeline-what-happened-with-the-nhs-covid-19-app/

that the centralised model would be greatly superior in its epidemiological and analytical capability, exacerbated the sense of policy incoherence, especially as a bespoke secure analytics environment had been designed to process the centralised data and needed to be completely rethought for the much more limited data that the decentralised model made available.

EAB's outputs and governance effects were fairly limited-its main output being a letter to the Secretary of State setting out an ethics framework for contact tracing apps, which was then taken forward as guidance for the next version of the app. EAB lasted only three months, but it would appear that it was nonetheless one of the high points for genuinely independent ethical scrutiny of U.K. government policy during the pandemic. Neither the redesigned app nor the broader Test and Trace programme that oversaw it had an independent ethics advisory board. This was despite the sheer scale of the Test and Trace programme (for which £37 billion was set aside) and the fact that Test and Trace posed many ethical issues about the sharing of confidential information that were at least as significant as the initial app proposal.

Clearly, the kind of high-profile media coverage EAB received was not something that the government found helpful. However, even before this, it was not obvious that there was a form of ethical scrutiny open to EAB that would have allowed it to do what its Terms of Reference required, namely, to ensure that the app was 'operating in line with ethical requirements, and is transparent and open to public scrutiny'34 while also allowing the government to maintain the kind of control that it seemed keen to maintain. As the final report noted:

> The EAB first met on 2 April 2020 and its existence was not publicly noted until a blog on the NHSX website on 24 April 2020, by which time advice had already been sent to the Secretary of State for consideration.35

Permission to publish EAB's letter and ethical framework depended on the Secretary of State, and this was not given until 13 May 2020, leading to a delay 'that, although short by the standards of non-COVID-19 practice, was unhelpful in terms of the role of the EAB in providing the public confidence that ethical issues were being given due consideration'.36

ETHICS ADVICE AFTER EAB

EAB allowed for a degree of independent and transparent ethical scrutiny, albeit only of operational rather than strategic elements of policy, and in circumstances that were far from ideal. The time afterwards saw the Westminster government's approach to public deliberation about issues of significant ethical importance become more obviously tokenistic. One salient example was the DHSC public consultation on mandatory vaccination for all frontline health and social care staff in England in October 2021. The consultation response document reports that 34,929 responses were received, with 8.3 million words of free text.³⁷ The time between the close of the consultation and publication of the government response recommending that the policy go ahead was 11 working dayssuggesting an incredible feat of speed reading by DHSC, or a consultation in bad faith.

One body did play a sustained role in providing ethics advice to the government, namely, the Moral and Ethical Advisory Group (MEAG). MEAG was set up pre-pandemic in 2019 to provide 'independent advice to the UK Government on moral, ethical and faith considerations on health and social care related issues' in respect of 'health related incidents including but not limited to pandemic flu'. 38 The United Kingdom already had an ethical framework for pandemic influenza planning in 2019, which MEAG adopted.³⁹ In April 2020, MEAG offered to produce an ethical framework for use by policymakers in Covid-19, which would be consistent with the pandemic influenza ethical framework. This suggestion was not accepted by the Chief Medical Officer (CMO). 40 Nor was the existing pandemic influenza ethical framework used by the government in articulating rationales for policies. 41

MEAG kept a very low profile during the pandemic. Its mode of operation was responsive, answering topics and approaches given to it by external bodies. 42 Brief minutes of many of MEAG's meetings were made public, though often with a significant delay. Minutes for meetings after April 2021 were only made public at the same time as MEAG's formal closure in October 2022. No formal correspondence or advice was made public, and hence no government responses to this correspondence either. In fact, a close reading of MEAG's minutes gives reason to doubt, from the perspective of policymakers at least, that provision of formal advice or recommendations was in fact MEAG's goal. For example, the MEAG minutes from 20 January 2021 relay the following advice from CMO Chris Whitty: 'CMO valued the presence of the MEAG and the ability to understand

³⁴lhid: 18

³⁵EAB, op. cit. note 20, p. 12.

³⁶ lbid: 12.

³⁷Department of Health and Social Care. (2021). Making vaccination a condition of deployment in health and wider social care sector: Government response to public consultation (pp. 5 and 16), https://assets.publishing.service.gov.uk/government/uploads/system/ uploads/attachment_data/file/1032203/making-vaccination-a-condition-of-deployment-inthe-health-and-wider-social-care-sector-government-response.pdf

³⁸Moral and Ethical Advisory Group. (2020). Moral and Ethical Advisory Group (MEAG): Terms of reference, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/ $attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/876043/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/87604/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/87604/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/87604/Moral_and_Ethical_Advisory_Group_-_terms_of_attachment_data/file/87604/Moral_and_Group_-_terms_of_attachment_data/file/87604/Moral_and_Group_-_terms_of_attachment_data/file/87604/Moral_and_Group_-_terms_of_attachment_data/file/87604/Moral_and_Group_-_terms_of_attachment_data/file/87604/Moral_and_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Group_-_terms_of_attachment_Gr$ reference.pdf

³⁹Cabinet Office and Department of Health (2007). Responding to pandemic influenza: The ethical framework for policy and planning. Department of Health.

⁴⁰See Moral and Ethical Advisory Group. (2020). *Meeting summaries*, for 22 and 29 April 2020. https://dhexchange.kahootz.com/MEAGpublications/view?objectId=128443685

⁴¹Gadd, E. (2020). Is the Government using its own ethical framework? https://www. nuffieldbioethics.org/blog/is-the-government-using-its-own-ethical-framework

 $^{^{42}}$ MEAG will provide independent, timely and coordinated moral, ethical and faith related advice in response to questions and issues put to it' (Ibid.) MEAG's Terms of Reference envisaged the possibility of its undertaking proactive work, but it did not do so during the Covid-19 pandemic. Those who were able to request a MEAG meeting included the U.K. CMOs, Ministers and MEAG's sponsors in DHSC.

complexities, however counselled against producing documentation that offered recommendations, given the political aspect of decision making'. ABAG thus took on a role as a kind of sounding board, and seems to have maintained what influence it did have by a combination of discretion and, it would appear, limiting its role to articulating the ethical considerations in play (what we describe in the next section as an Ethics Arbiter role), rather than provision of ethical advice about what should be done.

The lack of explicit articulation of ethical frameworks, or even mention of the ethical values in play, in the government response to the pandemic was noted by many commentators.44 NCOB would have been an obvious place for the Westminster government to turn for high-quality independent ethics advice that was well calibrated for policymaking purposes, given that it was the closest body that the United Kingdom had to a National Ethics Committee. Nonetheless, NCOB's advice was not sought, to its evident frustration, and it published a statement entitled 'COVID-19 and the basics of democratic governance' on 25 April 2020, noting a range of 'critically important issues that affect many people-indeed everybody', on which 'Westminster Government does not seem to want to engage or take on board other views... nor is it evident that they are thinking about them, or taking advice on them from a social and ethical perspective'. 45 Together with Involve, the nation's leading public participation charity, NCOB wrote an open letter to the Prime Minister on 28 April 2020, reminding him that 'Engaging with, and accounting in a transparent way to, all sections of society for the decisions that are taken is essential for trust and trustworthiness'. 46 The letter was not answered.

The overall picture that forms is one of a government uncomfortable with conducting authentic ethical debate in public. Even MEAG, the ethics body in which it seems to have placed most trust, was asked, for political reasons, to refrain from undertaking the kind of weighing of ethical reasons that would have been necessary to provide genuinely independent guidance for government decision-making. The Westminster government's evasion of explaining or debating the ethics of its Covid policies in public clearly fell short of the Openness and Accountability called for by the Nolan Principles and the Good Decision-making principle of the *Pandemic Influenza Ethical Framework*. It was unfortunately accompanied by a set of broader failures of standards of conduct in public life that came to light either

contemporaneously or retrospectively,⁴⁷ leading to a widely remarked crisis of standards in public life.⁴⁸

7 | RECOMMENDATIONS AND CONCLUSIONS

Our analysis has revealed two fundamental dimensions on which translational bioethics for policy can differ, which, when combined, give us four ideal types. ⁴⁹ The first dimension is whether someone aims to provide an analysis from their own perspective or from the perspective of the public interest. As we saw earlier, thinking from the perspective of the public interest will require the bioethicist not just to think from their own perspective but also that of other citizens, and may require them to accept certain legitimate constraints on the kinds of reasons that are deemed relevant.

The second dimension is whether the analysis aims to give an ethical recommendation about what is to be done in response to a specific policy question. Ethical analysis might stop short of making a specific policy recommendation for various reasons. In many cases in philosophy and bioethics, analysis aims to answer an ethical question about an idealised scenario or to establish an abstract principle, and will remain silent about the implications for real-world decision-making. ⁵⁰ In other cases—as we saw with MEAG—an individual or group may seek to give an account of the ethical considerations that are relevant to a decision, without recommending what should be done.

Together, the two dimensions provide four ideal types:

- 1. The Pure Ethicist. The pure ethicist does not take on a role in public policy formation. They believe that the task of high-quality ethics research is best served in isolation from the contingent constraints of public policy: pure ethicists do not need to be immersed in how public policy operates in order to carry out good research. Hence, it is never a defect of ethical research that it has no utility or is carried out in a manner that is detached from or does not aim to engage with public policy.
- 2. The Advocate. The advocate seeks to engage decision-making processes with particular outcomes in mind. On this approach, the best or main role and value of ethics research lie in providing arguments for particular political causes. NGOs, whose role is to advocate for the interests of a particular group, frequently adopt

⁴³Moral and Ethical Advisory Group. (2021). *Meeting summaries*. https://dhexchange.kahootz.com/MEAGpublications/view?objectId=128443685

⁴⁴See, for example, Gadd, E. (2020). *Is the Government using its own ethical framework?* Retrieved July 14, 2022, from https://www.nuffieldbioethics.org/blog/is-the-government-using-its-own-ethical-framework; Fritz, Z., Huxtable, R., Ives, J., Paton, A., Slowther, A. M., & Wilkinson, D. (2020). Ethical road map through the covid-19 pandemic. *BMJ*, *369*, m2033. https://doi.org/10.1136/bmi.m2033

⁴⁵Nuffield Council on Bioethics. (2020). *COVID-19 and the basics of democratic governance*. https://www.nuffieldbioethics.org/news/statement-covid-19-and-the-basics-of-democratic-governance

⁴⁶Nuffield Council on Bioethics and Involve. (2020). Open Letter to Prime Minister. https://www.nuffieldbioethics.org/assets/images/COVID-19-joint-letter-to-Prime-Minister-28-04.pdf

⁴⁷For a timeline, see Halliday, J. (2022, July 1). Scandal after scandal: Timeline of Tory sleaze under Boris Johnson. *The Guardian*. https://www.theguardian.com/politics/2022/jul/01/scandal-timeline-tory-sleaze-boris-johnson

⁴⁸Stewart, H., Syal, R., & Elgot, J. (2022, June 1). Ethics watchdog says PM has failed to allay fears he is above the rules. *The Guardian*. https://www.theguardian.com/politics/2022/jun/01/boris-johnson-standards-committee-ministerial-code-ethics

⁴⁹Our model draws on Pielke Jr.'s model of roles within science advice and Scully's account of advocacy in bioethics. See Pielke, R. A. (2007). *The honest broker: Making sense of science in policy and politics*. Cambridge University Press; Scully, J. L. (2019). The responsibilities of the engaged bioethicist: Scholar, advocate, activist. *Bioethics*, 33(8), 872–880.

⁵⁰Wilson, J. (2021). Philosophy for public health and public policy: Beyond the neglectful state. Oxford University Press, Chapter 3.

this role, but it is one that may also be adopted by scholaractivists.

- 3. The Ethics Arbiter. The ethics arbiter aims to help politicians and/ or publics understand the ethical values and reasons that are relevant to a specific policy context, but without taking sides. The arbiter aims to equip others with resources to reach their own decisions. This role is breached if and when they lapse into advocacy for particular solutions or options.
- 4. The Critical Friend. The critical friend aims to provide advice and to challenge a public institution, helping it to articulate an account of the public interest or common good and act on this basis. Rather than simply indicate the available options, the critical friend is not afraid to say that some options are preferable to others. This advice is shaped by an accurate and sympathetic understanding of the kinds of constraints that an institution faces-where these constraints are determined both by prior democratic deliberation (e.g., an institution's foundational values and stated purpose) and factors such as resource and political feasibility.

Both the Pure Ethicist and the Advocate thus speak from a partial perspective. Their interventions need to be combined with others' perspectives in order to get to a comprehensive account of where the public interest lies-either because they do not aim to say anything of policy relevance in the first place (Pure Ethicist) or because what they say aims to advocate for one group or cause while staying silent about others that may be equally or more deserving (Advocate). Both the Ethics Arbiter and the Critical Friend, on the other hand, aim to speak from a public perspective that already incorporates appropriate sensitivity to all contextually relevant ethical considerations. The Ethics Arbiter aims to clarify these ethical considerations without taking a stance on what should be done, whereas the Critical Friend does advise on where the balance of public interest lies.

We put these four roles forward as ideal types, in awareness that some interventions may fall between the four roles, and that the same individual or committee may act in more than one of these roles in different contexts. Nonetheless, distinguishing these roles clarifies the terrain. Common challenges include when the same individual acts in more than one of these roles in respect of the same issue, and where there is unclarity about the role that a person or committee is being asked to play with their ethics input into a policy process.

Things are unlikely to turn out well unless the policymakers seeking ethics advice, and committees providing it, agree about whether the committee's role is that of an Ethics Arbiter, or of a Critical Friend and whether being a member of the committee is compatible with simultaneously adopting an advocacy role outside of the committee in respect of the same issues. EAB's terms of reference suggested that it was asked to provide critical friendship, but in practice, things were different. As with MEAG, it appeared that some policymakers would have been far more comfortable with EAB adopting an Ethics Arbiter role. Some EAB members were prominent privacy advocates in their roles outside of EAB and had argued publicly against the centralised approach to data collection that was

at the time a key element of the app's design. This may have made it more difficult for the committee to maintain policymakers' confidence that it could perform the role of an ethics arbiter.

After the demise of EAB, the Westminster government's response was marked by how little independent ethical scrutiny and challenge, of any of our four ideal types, was incorporated into decision-making processes. Where ethical analysis was sought, it was, as we saw with MEAG, assigned an ethics arbiter role and the substance of the analysis remained largely private. In other cases, such as the consultation on mandatory vaccination of NHS workers, what was presented as public consultation was obviously tokenistic. Such behaviour is difficult to reconcile with the standards laid out in the Nolan Principles of Public Life or with more general norms of democratic governance.

The ability of bioethicists—whether in the role of Pure Ethicists. Advocates, Ethics Arbiters or Critical Friends-to influence policy is dependent on broader institutional structures. It requires that policymakers are aware when their policies touch on ethical issues that it would be beneficial to have a broader view on and to be comfortable enough to open a public conversation on the ethical issues that are in play in a context, and how they might be reconciled. Even where there is such willingness, it requires sufficient absorptive capacity⁵¹ within public institutions to engage with the results of ethical reflection. Clearly, factors such as the presence, or absence, of a National Ethics Committee and the infrastructure that supports it may make a significant difference to a government's willingness to open ethical debate and its ethics absorptive capacity. Both lack of willingness to engage in public ethical debate and lack of ethics absorptive capacity seem to have played a role within the Westminster government's response.

Each of the four ideal types of ethics analysis can play useful roles in public deliberation about what should be done. However, the degree of absorptive capacity required from public institutions to make use of novel ethical insights depends also to a significant degree on the skill with which bioethicists can translate their work into a form that is intelligible to policymakers, relevant to the decision to be taken, and available at the right time. The absorptive capacity required to make use of an academic article presented as pure ethics is much greater than that required to assimilate a well-targeted briefing produced from the perspective of a critical friend or ethics arbiter. This is one reason why contributions envisaged as pure ethics rarely have much effect on policymaking, at least in the short term.⁵²

Despite the Westminster government's failure to follow the standards that it itself espouses as necessary for public life, it is important not to draw the cynical conclusion that ethical reflection

⁵¹Cohen, W. M., & Levinthal, D. A. (1990). Absorptive capacity: A new perspective on learning and innovation. Administrative Science Quarterly, 35(1), 128-152.

⁵²Ideas can and do move from pure ethics into public bodies, so long as skilled translators are present—this is exhibited in the take-up of Onora O'Neill's work on trust and trustworthiness, as popularised in her Reith Lectures into a range of public bodies such as the Office for National Statistics's Code of Practice for Statistics (2022). https://code.statisticsauthority.gov. uk. However, this dissemination is often haphazard and is unlikely to occur in a timeframe necessary for aiding a pandemic response.

never makes a difference in public policy or that ethical scrutiny will inevitably be reduced to ethics-washing or worse. ⁵³ The concept of public interest remains crucial for articulating and justifying public policy in liberal democracies, and it is an ethical ideal. To be sceptical about the possibility of genuine, fruitful and open debate about public values, or to be sceptical about the likelihood of politicians and public servants taking seriously the requirement to act in the public interest, is to be sceptical about democracy itself.

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CONFLICT OF INTEREST STATEMENT

Prof James Wilson was a member of the Ethics Advisory Board (EAB) for the NHS Covid-19 App and is a member of the National Data Guardian's panel. The article refers to the work of the NDG and EAB, but the views expressed are solely the authors' and do not necessarily represent the views of EAB, NDG, the NDG panel or any other organisation, committee, group or individual.

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