Introduction

Diagnostics, Medical testing, and Value in Medical Anthropology

Alice Street and Ann H. Kelly

The process of diagnosis—assigning an individual with illness to a standard disease category—is foundational to modern biomedicine. As numerous anthropologists, sociologists, and medical historians have shown, diagnosis is also fundamentally a social and cultural practice (Blaxter 1978; Brown 1990; Rosenberg 2002; Jutel 2009, 2015). Diagnostic categories and processes are central to the production and distribution of biomedical authority (Armstrong 2011; Rosenberg 2002). A recognised diagnosis confers legitimacy on the patient's status as 'sick' and mediates access to support and resources (Jutel and Nettleton 2011; Petryna 2013; Price this issue). It can be both a form of social control (Brown 1990) and the basis for new solidarities and subjectivities (Rose and Novas 2005). Diagnosis is also a contested domain, both because of the uncertainties that are integral to the process of fitting an individual case into a universal category, and due to social and political contestation over the meaning, content and implications of particular disease categories—or their absence (Nettleton, Kitzinger, and Kitzinger 2014; Pickersgill 2014; Smith-Morris 2015).

Until recently, the burgeoning field of anthropology and sociology of diagnosis has focused on diagnosis as primarily a process of classification and labelling (e.g., Brown 1990; Jutel 2009; Jutel and Nettleton 2011; Armstrong 2011; Smith-Morris 2015; Manderson 2020). The contributions to this special issue, by contrast, focus on the relationship between diagnosis and the technical processes of testing that inform it. The *in vitro* investigation of biological specimens taken from the human

body has, as medical historians often remind us, long been a hallmark of modern medicine (Ackernecht 1967; Cunningham and Williams 1992; Armstrong 2011; Löwy this issue). Alongside the rise of pathological anatomy, the emergence of laboratory medicine in Europe in the late nineteenth century helped to consolidate the shift in medical cosmology from 'bedside medicine', which defined disease in terms of its 'external and subjective manifestations', to 'hospital medicine', in which expert investigators identified hidden pathogens as the cause of patient illness and categorised those pathogens as objective disease entities (Jewson 1976). With these transformations, according to Jewson, 'medical practise became an appendage to the laboratory' (1976, 230). While other medical historians have provided a more nuanced picture of the emergence of modern medicine in the 19th and 20th centuries, it is difficult to dispute the fact that laboratory testing has come to occupy a central place in contemporary medical epistemologies, interventions, and practices.

Laboratory medicine, of course, only travelled as far as testing infrastructure would take it, a point often overlooked by historians of European medicine (Street 2018). Nonetheless, the fundamentals of laboratory investigation are included in medical education syllabi worldwide as essential tenets of medical practice. Having blood drawn is a common feature of a visit to the doctor, maternal health clinic, or hospital in at least the well-resourced pockets of most health systems. Point-of-care tests for infectious diseases such as malaria, HIV and other sexually transmitted infections, and for emerging viruses that cause diseases such as COVID-19, are increasingly available—often for private purchase and self-administration—in places where laboratory infrastructure is lacking. Concerns about spiralling drug prices, antimicrobial resistance and emerging disease outbreaks have all contributed to heightened awareness of the need for accurate and accessible diagnostic testing in global health (Chandler 2019; Pai et al. 2012). By virtue of studying people's everyday engagements with medical systems, anthropologists therefore frequently encounter medical tests—whether in the form of biological samples, laboratory assays, material devices, or medical records—even if they have not always been the focus of our attention.

Some key domains of pioneering scholarship provide a way of navigating the socio-material particularities and peculiarities of medical testing. Work on the gendered moralities of reproductive and newborn testing, for instance, has shown that tests can generate more uncertainty than they resolve, bring with them new burdens of responsibility, and open up raw emotional terrains (e.g., Birenbaum-Carmeli and Inhorn 2009; Timmermans and Buchbinder 2010; Rapp 2000). Elsewhere, research on the rise of genetic testing since the early 1990s has explored the shaping of risk-based subjectivities and the emergence of the 'patient-in-waiting' figure (e.g., Latimer 2007 Konrad 2003; Nelson and Robinson 2014).

And anthropological studies of point-of-care testing in so called 'resource-poor' settings have drawn attention to the values and assumptions embedded in the design of testing technologies, showing that in order for 'simple' technologies to work, there is often the requirement for the presence of the very same infrastructures that new rapid and portable testing technologies promised to replace (Beisel et al. 2016 Beisel, Calkins, and Rottenberg 2018; Engel and Krumeich 2020; Harper and Khatri 2019; Hutchinson et al. 2015, 2017; Kameda et al. 2021; Lee and Palmer 2018; Meinert et al. 2009; Palmer et al. 2020; Street 2011, 2018; Whyte, Whyte, and Kyaddondo 2018).

Despite the richness of these accounts, these threads of enquiry have tended to remain conceptually disparate, split among critical sub-communities and between, on the one hand, research focused on high-end laboratory-based technologies in high-income settings and, on the other, research focused on more frugal testing technologies designed for under-resourced health systems. The anthropology of medical testing has never quite flourished as a comparative field in its own right in the same way as has, for example, the anthropology of pharmaceuticals (Biehl 2004; Dumit 2012; Ecks 2005; Nguyen 2010; Petryna, Lakoff, and Kleinman 2006; Whyte, van der Geest, and Hardon 2003). The anthropology of medical testing, in other words, already exists. But further work is required to consolidate this research into a field of enquiry: to reflect on what we already know, develop a common analytical vocabulary, and establish fertile lines of exploration for the future. Key questions for such an endeavour include how socio-material processes of testing shape the work and effects of diagnosis, and, more broadly, what tests and testing do in and to social and medical worlds.

An impetus for greater consolidation and synthesis came in March 2020, when Dr Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization, insisted that the world 'Test, test, test' in response to the rapid global spread of a novel and deadly coronavirus (WHO 2020). The epistemological stakes of testing for the SARS-CoV-2 virus that causes COVID-19 disease could not be higher: the effectiveness of infection control, clinical triage, scientific developments, economic strategy, and public acceptance all hinged on the accuracy of diagnosis. 'Without testing', Dr Tedros put it, 'you are blindfolded'. The challenges of regulating novel technologies in public health emergencies underscored the complex moral values and fiscal virtues associated with diagnostic innovation, raising cross-cutting ethical questions from those around access, to those of safety, and of commercialisation (Kelly et al. forthcoming). The fragility of the trust placed in those providing testing and/or technologies, and the dependence of epidemic response on public 'compliance' with self-isolation guidelines in the case of a positive test result, opened a new frontier of consideration around the politics of diagnostic access and credibility. A similar

opening occurred, too, around the pragmatics of diagnosis: for whom and to what end was it taking place? (cf. Brhlikova et al. 2011).

Since Dr Tedros made those comments, testing has seldom been far from the public consciousness, particularly in places where the virus has hit the hardest. In many countries, including the UK, a stuttering start to the response—characterised by swab scarcity, uncertain regulation, and accelerated product development—has been followed by a proliferation of public testing centres, mobile surge-testing units, and private event or travel testing companies. They offer a plethora of testing technologies that target different biomarkers, use distinct sampling methods, come in a variety of physical formats, and are associated with fluctuating levels of accuracy (see also Beaudevin et al., and Löwy, both in this issue). Perhaps the most striking aspect of the 'new normal' for people living in these countries is the sheer *ubiquity* of COVID-19 medical testing. In the UK, for example, members of the public with no medical background or laboratory training now routinely keep rapid test 'kits'—comprising sample swabs, bottles of buffer, test cartridges, and waste bags—in their kitchen cupboards, ready to lay out on a pre-cleaned surface at the slightest tingle of a sore throat.

'Tests are everywhere, aren't they?' one of our primary-school-aged children observed to us recently. 'Well', goes the intuitive anthropological response, 'everywhere *here'*. In fact, the ubiquity of testing in high-income countries afflicted by high case rates only makes the scarcity of testing systems in many low- and middle-income countries starker (Kelley et al. 2020; Munharo et al. 2020). Such testing disparities are also reflected in the distribution of social research into COVID-19 testing, with the vast majority of studies on the topic focusing on high-income countries in the Global North (Bevan et al. 2021). Moreover, the fact that COVID-19 has brought the ethics and politics of medical testing to public attention does not mean medical testing was not already 'everywhere' before—only that, perhaps, it had less public visibility as a social, political, economic, and ethical 'problem'.

The sociocultural significance of practices of testing and of medical tests themselves have taken centre stage during the COVID-19 pandemic. Taking the immediate prominence of medical testing in the pandemic response as a provocation, *MAT* put out an open call for papers on medical testing, diagnosis, and value in May 2020. Our goal was to render explicit a latent field of anthropological research by exploring how studies of medical testing in diverse social and cultural settings might speak to one another conceptually and empirically. We were open about what might come within the purview of the topic, and ultimately included papers on the development of new diagnostic platforms and on testing data practices in addition to more classical medical anthropology

research into the deployment and use of medical tests in diagnostic processes. If medical anthropology is to make a meaningful contribution to our understanding of the new world of COVID-19 testing, then it must also look beyond the current pandemic to consider what the anthropology of testing has to offer in terms of furthering our understandings of medical testing as a social and cultural process more broadly. This, we argue, is a fundamentally comparative, ethnographic project.

In the remainder of this introduction, we elaborate on several themes that we identified as cutting across the ethnographic contributions to this special issue and which will, we hope, serve as prompts and provocations for future comparative work on the anthropology of medical testing. These themes include: the uneven geographies and unstable infrastructures of medical 'testscapes'; the relationships between testing and governance; the commoditisation of tests and the transformation of the value of testing in global health markets; and the relationships between medical tests and scientific, social, and ethical uncertainty. In the final section, we return to the question of what diagnostic tests *do* and argue for a pragmatic anthropology that focuses on who benefits from testing and what forms of 'public good' they produce.

Testscapes

For a start, an ethnographic approach to medical testing involves noticing the places where medical testing is not taking place and where testing products are absent. The geographical unevenness of testing follows the well-worn contours of inequities between the Global North and South (Okeke 2018; Wilkinson 2017). For instance, in this issue Bunkley examines the relationship between testing and diagnosis, showing that widespread scarcity of glucometers in Senegal, and weak disease reporting systems, contribute to the obfuscation of both the scale and type of diabetes in the country. Here the 'gold standard diagnosis' is based either on a fasting plasma glucose test or on an A1c glucose test, both of which require costly and time-intensive laboratory work and remain out of reach for most. By narrowing the epidemiological imagination of the scale and nature of disease in Senegal, this absence of diagnosis also inhibits global health investment in effective measures of disease detection and control.

A similar set of disjunctures animates Vernooij's descriptions of the improvisation work performed by laboratory technicians to stabilise unstable equipment in the clinical laboratory of a Sierra Leonean hospital. Here, we see how the 'diagnostic moment' (Jutel 2015; Smith-Morris et al. 2021; Bunkley, this issue) is attenuated by infrastructural instabilities: the unstable supply chains, electrical outages, malfunctioning equipment, and poorly paid laboratory staff. In Vernooij's article and

in the Field Note co-authored by Bah, Vernooij, and Street, diagnosis is a considerable achievement, made possible by investment of 'entrepreneurial staff' who privately procure materials to fill in the gaps, a charge which they offset by covertly charging patients for results. In a radically patchy diagnostic landscape, laboratory work often remains hidden and under-valued, but the meanings and value of medical tests for the people who conduct them can have far-reaching implications for patients.

However, if 2020 has taught us anything it is that the absence of testing is not only an issue for low- and middle-income countries. Beaudevin et al. examine the ways in which the 'scarcity' of testing infrastructure at the start of the outbreak in France framed possible responses to the COVID-19 pandemic and ultimately led to the decision to resort to lockdown. Attending to the varied ways in which diagnostics worked in practice—as, alternately, public health and clinical tools—the authors complicate a straightforward and highly politicised discourse of scarcity, pointing instead to the specific sites where testing could be carried out, examining by whom and for what purpose. Despite their testing capacities, private laboratories were excluded from a national response since they lay outside both the socio-technical networks that have circumscribed France's pandemic response, and the nation's fragmented institutional jurisdictions. These two systems exist under continual threat from fiscal constraints and administrative reconfigurations and determine how infectious disease control takes place. Material scarcities, while real, are amplified and refracted by divergent testing terrains which do not mirror the territory of the nation state, seeding a governmental il-logic that remains entrenched in France's pandemic response, even after tests have become widely available.

Testing governmentalities

Several of the contributions to this issue explore the interstices of testing and governance. For Beaudevin et al., the complex discourses and realities of testing scarcities provide a map of governmental deficiencies that are only amplified in an emergency. In their account, tests entail political risks, as diagnostic targets are missed and fail to do the work expected of them in opening up the economy following national lockdown (see also Boswell 2020). Kameda's analysis presents a compelling counterexample of how testing capacity can actually generate a national imaginary. Kameda explores national efforts to develop blood bank tests as an exercise in sovereignty, one that requires a robust national imaginary to sustain. Kameda's account underscores the political value of diagnostic infrastructure, showing how government-built molecular tests create the conditions of Brazil's technological sovereignty.

Other contributions draw more explicitly on a Foucauldian frame of reference to explore the role of medical tests as technologies of governance and tools of subjectification. The contributions by Chowdhury and Basu and by Price both show that the bureaucratisation of medical testing (which enables testing to be deployed as a technology of governance) depends on the elision of nuance in test results and the erasure of subtle differences in their biological meaning. During the COVID-19 pandemic in India, as Chowdhury and Basu discuss, testing databases became the basis for a form of 'government by database' which, ultimately, led to a focus on the maintenance of the database itself as opposed to the maintenance of public health. In a similar vein, Price shows how the incorporation of COVID-19 tests into legal apparatus for determining the right to work in the United States gave rise to a form of 'diagnostic citizenship' in which test results become bureaucratic instruments that are divorced from any medical significance they might possess.

The contributions from both Löwy and Whitacre are concerned with the politically and ethically problematic status of the 'asymptomatic carrier' of infectious disease in public health governance. As Löwy demonstrates, the category rises with the dawn of laboratory testing and, with it, new and highly fraught capacities of public health governance. She shows how the persona of the asymptomatic carrier embodies the entrenched tensions between the liberty of the infectious-yet-healthy and the prophylactic exigencies of public good in an outbreak. Whitacre likewise explores the history of HIV testing in the US and in global health, showing how public health and legal mandates sought to strike a balance between the value to public health of people disclosing their positive HIV test result, and the right to privacy of the individual. These competing elements ultimately gave rise to a whole field of HIV public health research premised on the confessional practices (including diagnostic disclosure) of research subjects.

Through a comparative history of typhoid, HIV and COVID-19, Löwy shows how public health responses to this conundrum of the asymptomatic carrier, who is not sick themselves but represents a threat to others, have consistently played out in ways that reinforce racial and class inequalities. In infectious disease control, testing not only differentiates diseases, but also the infectious from the non-infectious, highlighting the role of tests as a technology of government and as a mechanism for social division.

Testing markets

Kameda's work in this issue shows that the test is the outcome of an innovation-driven economy. One set of value contestations plays out along tensions between the value that diagnostic tests hold for people as commercial products and their

value for people's health. Vasquez describes how the development of tests by the philanthrocapitalist Carlos Slim's Foundation in Mexico that detect risk of diabetes both transform's people's relationship to chronic disease risk while opening up new markets in public health. Ultimately, Vasquez implies, these tests are primarily designed for the generation of private financial—as opposed to public health— value (cf. Hayden 2007).

In a similar vein, Whitacre explores the bioeconomy of diagnostic testing for HIV, showing how HIV testing in public health research feeds into a drug development infrastructure, posing the question of whether confessional practices such as disclosure of test results should be considered as a form of labour. Vernooij similarly explores tensions between economic and public health value, though in this case in the context of profound infrastructural instability in Sierra Leone. Together with the Field Note by Bah, Vernooij, and Street, this research shows how the undervaluing of diagnostic work in Sierra Leonean health institutions leads to informal exchanges in which the value assigned to tests as sources of livelihoods takes priority over their life-saving capacities.

In several of these cases, what appears to get lost in the marketisation of diagnostic tests is the question of what value a test might hold for the person being tested. Vasquez, for example, shows that a pre-diabetes diagnosis is essentially meaningless for patients as they would have received the same public health advice irrespective of the test result. Widmer's Position Piece on direct-to-consumer (DTC) microbiome tests points to how future users are imagined specifically not as patients, but instead as empowered consumers, driven by a commitment to self-knowledge and personal improvement, captivated by producers of new healthscapes that incorporate diverse forms of life in order to optimise wellbeing. The making of that producer/consumer—or what she terms 'prosumer'—is simultaneously a process of financial subjectification, as users provide biological materials to be prospected, often by for-profit companies.

In those elisions between health citizenship and bioeconomy, however, Widmer sees potential: tests create the conditions for a microbiopolitics positioned against the public health, agricultural, and biomedical practices that underpin the *dis-eases* of contemporary capitalism. Even in situations where science is looking for a return on investment, we might ask what value tests hold for the people who develop, work with, or encounter them—a lived experience that is not always predictable or straightforward.

Testing uncertainties

The clinical and/or public health value of medical tests is often linked to the diagnostic certainty they can provide. Yet the sociology of diagnosis has long

highlighted the uncertainties and anxieties that diagnostic testing can generate, especially when deployed for the purpose of screening 'healthy' populations (Gillespie 2012; Armstrong and Eborall 2012; Timmermans and Buchbinder 2010; Lupton 2012). Several of the contributions to this special issue build on this insight by highlighting the uncertainties and ambivalences generated by medical testing. Arteaga Pérez's analysis of new diagnostics based on biomarkers that could, at least in theory, predict tumour evolution provides insight into the scientific uncertainties that underpin the development of novel diagnostic tests. She shows the process of validating the 'raw signals' of future disease to be one fraught with ambiguities and requiring extensive labour and infrastructural investment. Once developed tests reach the point of use, as Janssen et al. discuss in their contribution to this issue, at which point, further uncertainties pertain as to whether to test, how a test is to be conducted, and whether its results are accurate, but also to broader ambivalences about the purposes and meanings of test results and their clinical, social, economic and personal consequences.

In several contributions to this issue, diagnostic uncertainty is shown to generate anxiety and ambivalence for the persons undergoing testing. Janssen et al. explore the role of HIV oral self-testing in generating the at-risk subject, which they analyse through the concept of 'living under HIV', building on the conceptualisation of 'living under diagnosis' developed by Lenore Manderson in a previous *MAT* special section (Manderson 2020). In a high-prevalence setting where there is a high chance that a positive test result is a true positive, uncertainties around test conduct and interpretation are experienced as intensely stressful for participants—an aspect of testing that gets lost in policy prescriptions around improving user conduct and compliance.

The ethics of inhabiting those subject positions become perhaps even more fraught when the diagnosis is still to be determined. In the research article by Janssen et al. it is the at-risk status of individuals that makes them eligible for testing (or, as in the article by Whitacre, participation in public health research that involves testing). But in the context of predictive diagnostic testing it is risk itself that testing helps to diagnose. Drawing on Das's notion of ordinary ethics, Frumer et al., for instance, explore the ways that monitoring for lung cancer following a pre-diagnosis poses ethical questions for patients about how to live a good life in the shadow of death, but also what 'good', if any, comes from the knowledge of their cancer risk, raising the prospect that medical tests may sometimes accrue negative value for those who receive their results. That state of anticipation can give an existential torque to mundane life, as patients are forced to undertake perpetual close readings of their individual bodies, attending to emerging signs of impending death and making attempts to forestall it.

Testing anxieties, as Price's contribution shows, are also intensified when tests are assigned an authority that exceeds their biological capacities to generate meaningful results. There are many scientific reasons why a biomarker may not indicate the presence of an active infection. This is precisely why tests are usually only one aspect of the diagnostic process and require expert interpretation. Yet governmental bureaucracies are often highly constrained in their capacity to accommodate these ambiguities and instead short-circuit the diagnostic process to conflate test result with diagnostic label. As Price demonstrates, in the case of people who receive 'persistent positives' for SARS-CoV-2 infection, the 'disconnect between the biological and the biopolitical' can have far reaching repercussions for livelihoods and wellbeing.

Towards an anthropology of medical testing: Diagnostic pragmatics

As a whole, the collection speaks to the multivalent nature of medical testing. We encounter situations in which tests are deployed as research tools (Whitacre; Arteaga Pérez); as tools of epidemic control (Löwy; Beaudevin et al.); as instruments of subjectification and citizenship (Price; Janssen et al.; Widmer); as the genus of epidemiological reason and aporia in clinical care (Bunkley; Bah, Vernooij, and Street); as sites of economic exchange (Vasquez; Vernooij); and as exercises in governmentality and extensions of sovereign power (Chowdhury and Basu; Frumer et al.; Kameda). The multiple purposes to which medical tests can be put highlights the importance of a dedicated anthropology of medical testing, as opposed to testing being subsumed into the anthropology or sociology of diagnosis. But beyond an invitation to ethnographic scrutiny, the fundamental elasticity of testing—moving from laboratory bench to bedside, and from boardroom to courthouse and houses of parliament—also raises important questions about fundamental discrepancies in the expectations that testing generates, and in the work tests are being asked to do, for whom, by whom, and to what specific ends.

A concern with the pragmatics of testing cuts across these contributions which, when considered together, provide the opportunity to follow the production of social, medical, political, and economic realities at the point where diagnostic devices are deployed and testing is performed. Those enactments transcend the moment of clinical diagnosis, making disease doable across a variety of contexts and scales, creating new avenues for action, opening up possibilities for intervention while foreclosing others (Fujimura 1987). As Vasquez (this issue) deftly puts it, diagnostics help to define 'what constitutes actionable risk and for what public health action should aim to achieve'.

What is doable, of course, is not always what *should* be done; and it is on testing's normative orientation that Rosengarten focuses her concern. Drawing from speculative process philosophy, Rosengarten seeks to recentre the sentience, creativity, and labour of individual bodies on the production of biological knowledge. If, as she argues in her Position Piece, we repopulate a singular diagnosis with somatic signs and intelligence, which are necessary to render disease visible, then we can repair often violent abstractions of diagnostic taxonomies and reconnect biomedical categories to the lived experiences of the patient. Extending the commitments of a pragmatic tradition, Rosengarten suggests how we can begin to read value as *immanent to* medical realities, rather than as the commitments, perspectives, and concerns that precede that arrival at a biological fact. Perhaps this is ultimately where an anthropology of testing can provide most traction—in holding in abeyance the compulsion to 'test, test, test' long enough to consider the normative valence of the interventions those tests precipitate. Rather than criteria of diagnostic accuracy, ethnographies of testing in context offer pathways for considering the complex consequences of testing— representing new trajectories along which tests can be evaluated by the resources they offer for deliberation over the nature of public good.

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About the authors

Alice Street is a Senior Lecturer and Chancellor's Fellow in Social Anthropology at the University of Edinburgh. Alice's current research focuses on the design, development, and deployment of diagnostic devices in global health, for which she has received funding from the Scottish Chief Scientist Office, the Scottish Funding Council and the European Research Council. She has carried out research on global health interventions and health system strengthening in Papua New Guinea, India and Sierra Leone, and is the author of *Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinea Hospital,* published by

Duke University Press. She is a member of the Editorial Collective for *Medicine Anthropology Theory*.

Ann H. Kelly is Professor in Anthropology and Global Health and Interim Head of the Department of Global Health & Social Medicine at King's College London. Her ethnographic work focuses on the socio-material conditions that structure the production of global health knowledge, and the local ecologies of labour that circumscribe its circulation and use. She is currently collaborating on a number of transdisciplinary collaborations at the interface of infectious disease control, health system strengthening and global outbreak response and serves on the WHO Strategic Advisory Group of Experts (SAGE) for Ebola Vaccines and Vaccination. Recent work has appeared in *Cultural Anthropology*, *Social Studies of Science*, *Social Science and Medicine*, *Economy and Society*, *American Ethnologist* and *Visual Anthropology*.

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